RE-DOING PATIENT EXPERIENCE THROUGH DESIGN-LED RESEARCH

Alison Thomson

Thesis submitted for the degree of Doctor of Philosophy (PhD)

MARCH 2019
DESIGN DEPARTMENT
GOLDSMITHS, UNIVERSITY OF LONDON

Decleration

I declare that this thesis and the work presented in it is entirely my own. Where I have consulted the work of others, this is always clearly stated.

Alison Thomson

Acknowledgements

This thesis would not be complete without my two very patient supervisors, Alex Wilkie and Bill Gaver. Alex, thank you for your continued guidance throughout the literature and for your attention to detail. Bill, thank you for encouraging me to stay true to the practice and for sharing your unique perspective on design research.

This thesis would not have been possible if I had not met Gavin Giovannoni and the Barts MS research group in 2011. Gavin - thank you for the opportunity to work with you and for always believing in me. A special thank you to David Baker for your patience, your creativity and humour, which has given me the most wonderful experience of entering the world of MS research. And to the rest of the team - Monica Marta, Klaus Schmierer, Ruth Dobson, Rebecca Aldam, Ben Turner, Sharmilee Gnanapavan, Freya Edwards, Grace Anjorin and Angharad Davis – thank you for welcoming a designer to your team. I am also very grateful that I met Carol Rivas who has been an ambassador for my contributions to the field and for mentoring my development as a researcher.

This work was funded by a PhD studentship grant from Novartis and the MOT study was funded by the Horne Family Foundation Trust – thank you both.

The practice based work in this thesis involved Karen Hoffman, Harriet Smith and the inspiring participants of the study. I am greatly thankful for their time and efforts. Many people with MS have contributed to this work through the Barts MS Advisory Group – thank you Patrick, Bonnie, Elizabeth and Mark - and the many readers of the Barts MS Blog. Thank you all for sharing your insights with me.

My experiences with my PhD By Design colleagues - Maria Portugal, Bianca Elzenbaumer and recently, Sören Rosenbak - has helped me find my place in the design research community and given me motivation when times have been difficult. I also want to warmly thank the fellow researchers who have shared their PhD journey with me - Paulina Yurman, Sarah Pennington, Matthew Plummer-Fernandez, Nicola Gray and Sandra Neves. And of course, my oldest and best friend, Kirsten Darling-McQuistan.

It has taken a monumental amount of commitment, stamina and self-motivation to complete this PhD – all skills I have learnt from my friends and team mates at Kent AC. Thank you for showing me the importance of always showing up.

I am very lucky to have such a supportive family, that have encouraged me throughout this process. Thank you Janette, John, Michael and Scott. Finally, thank you Adam. It's taken me many years to get here, I needed this time, and you have been there for me every day. It's finished!

Table of Contents

List of Figures

All images were taken by the author unless otherwise stated.

List of Abbreviations

ANT	Actor-Network Theory
CCSVI	Chronic cerebrospinal venous insufficiency
DMT	Disease Modifying Therapy
EBCD	Experience Based Co-Design
ECTRIMS	European Committee for Treatment and Research in Multiple Sclerosis
EDSS	Expanded Disability Status Scale
FDA	Federal Drug Association
HCI	Human Computer Interaction
HRA	Health Research Authority
HRQoL	Health Related Quality of Life
MRI	Magnetic Resonance Imaging
MS	Multiple Sclerosis
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NRES	National Research Ethics Service
PD	Participatory Design
PML	Progressive Multifocal Leukoencephalopathy
PPI	Patient Public Involvement
PPMS	Primary Progressive Multiple Sclerosis
PROM	Patient Reported Outcome Measure
PUS	Public Understanding of Science
QMUL	Queen Mary, University of London
RRMS	Relapsing Remitting Multiple Sclerosis
SPMS	Secondary Progressive Multiple Sclerosis
SSK	Sociology of Scientific Knowledge
STS	Science and Technology Studies

Abstract

This thesis researches and examines how 'patient experience' is understood and approached through practice in healthcare, social science and design. In the UK, there is a considerable effort to access, measure and improve patient experience in the National Health Service (NHS). It is considered to be something that can be defined and thus made available for intervention alongside and in ways comparable to measures of clinical effectiveness and safety.

As such, current approaches to patient experience from healthcare, social science and design will be set out, identifying different assumptions that figure the patient and patient experience in radically different ways. The thesis will then go on to use the notion of performativity to show how different methods and techniques – and their associated rationalities – that aim to capture, measure and improve patient experience actually produce and enact different versions of patient experience.

The empirical and practice-based element of this research is based with the Barts Multiple Sclerosis (MS) research team at Queen Mary University of London (QMUL). This team researches MS, a degenerative and chronic neurological disease affecting over 100,000 people in the UK. Through engaging with the empirical contexts of an outpatient clinic, a scientific conference and a measurement activity, this research will explore how patient experience is enacted in different contexts and consider the ways in which patient experience, as human/non-human arrangements, come into being and is made capable for action/inaction by way of measurement tools, misbehavior, practices of simulation and different experience phenomena.

This thesis will demonstrate that design-led research offers the opportunity to rethink or redo the patient experience, drawing on scholars in Science and Technology Studies (STS) to develop a methodological approach to deal with performativity of method and the multiple enactments of patient experience. Viewing interventions as performative will disrupt and provoke different forms of knowledge, methods and people, as well as revealing processes, practices and procedures (or technologies of experience) that articulate patient experience. These then contribute to the design of three research events where I set out to develop a new patient-reported outcome measure to produce alternative forms of patient experience. As will become evident, this aim proved to be misguided, if not impossible; instead, my contribution is a better understanding of the requirements of a new approach to working with an expanded notion of patient experience. This thesis concludes by reflecting on the implications of design-led interventions to study different versions of patient experience alongside expanding on how design researchers can empirically engage with this topic.

Chapter 1: Introduction

Most of us have been a patient at one point in our lives. Whether for something minor or life changing, we have sought health advice or medical expertise. For most, having to take health advice and recover is a temporary state. However, those living with a degenerative chronic disease such as multiple sclerosis (MS) are, and will always be, patients.

Since the 5th of July 1948, people living in Britain have had access to a publicly funded National Health Service (NHS) which has been, and still remains, free at the point of delivery. Yet, in recent years, the effects of an increasing and ageing population has put pressure on the service to deliver care at the same capacity. While this may be a disaster waiting to happen, the NHS seems committed to delivering care to the best of its ability. In 2003, the National Institute for Clinical Excellence (NICE) produced a national document which outlined how MS should be managed in primary and secondary care. This document enshrined principles for effective management, including the provision of person-centred care with more recent guidance from NICE outlining the components of 'good patient experience' in adult NHS service (NICE, 2012).

Similarly, Lord Darzi, the previous Secretary of State for Health, wrote a report that associated healthcare quality standards with patients' experiences (Department of Health, 2008). The report asserts patient experience is as important as clinical effectiveness and safety in defining high-quality care. The report also aimed to incentivise measuring efforts to improve patient experience with further policy outlining payments to hospitals based on quality measures. It is thought that by collecting patient experience data, the strengths and weaknesses in healthcare delivery could be identified, thus driving quality improvement through informing health service commissioning and promoting patient choice (Black and Jenkinson, 2009). Following this, gathering patient experience data became mandatory in all NHS trusts, along with standards and rights being introduced that patients could expect when receiving healthcare from the NHS (Great Britain and Department of Health, 2010).

These policy documents have enabled patient experience to be considered a key component in improving the quality of healthcare services provided by the NHS. They also show how the UK government and healthcare regulatory bodies are driving the patient experience agenda forward through introducing pressures to measure service performance through health outcomes.[1] The health service functions in a system of evidence-based practice where medical practice and decisions are based on the best existing evidence rather than solely the experience of clinicians, traditions or theoretical reasoning (Guyatt et al., 1992). Therefore, the health service required an empirical, evidence-based understanding of

1 Patient experience consistently features in the NHS Outcomes Framework which is a set of indicators created by the Department of Health and Social care to monitor how the NHS is performing in relation to health outcomes of adults and children (Department of Health, 2018).

the experience of patients to improve it. In other words, only by knowing what the patient experience is can they then determine how to improve it.

So, in this healthcare climate, patient experience is reported and accounted for during commissioning and service provision. Design is considered capable of changing, improving and creating patient and other healthcare experiences as it has already done within the commercial contexts of, for example, the entertainment industry. It has been used in the entertainment industry to form relationships between products and services for sale and for consumer needs based on commercial interests and consumer culture. Moreover, design, in relation to health experiences, works to create and alter the experiences of people, users and patients when interacting with health services, products, devices and information.

In other areas of healthcare, however, designers engage with the practices and procedures of medicine and research to explore and expand on the potential for design-led research to contribute to the research process. Within this space, they are challenging the knowledge practices of medicine and the healthcare service, making room for alternative conceptualisations of what it means to be a patient and further questioning who or what is capable of having experiences. This links to larger debates across different fields of research including design, medicine and social science where the nature of knowledge practices is being questioned, for example, in discussions about the positioning of quantitative and qualitative data, the accountability of practice-based research, the role of lay knowledge and the material turn in recent social-cultural and political theory.

Patient experience is a multidisciplinary area of study and practice where tensions exist between different kinds of expertise from everyday people's experiences of living with a chronic disease to designers' different ways of knowing and of practicing research, and medical researchers' experience-based knowledge. This topic is the focus of medicine, governmental policy, and practices from specialist fields of design while also being something that individual people can relate to if they have received healthcare. This is why it is my thesis topic. My motivations have also been influenced by my previous experience of working within the field of healthcare and design for the past eight years as a designer and a researcher. In this time, I have witnessed and been involved in an increasing number of initiatives, funding opportunities and research projects focussed on increasing the engagement and involvement of patients in healthcare as a direct effect of radical policy set out by the Labour government in the early 2000s to involve patients and the public in planning and changing services (Health and Social Care Act, 2001). From my experiences, I have developed the opinion that design plays a key role in these changes, and this is where I hope this thesis can contribute.

This introductory chapter starts with the background context of the thesis, explaining my collaboration with the Barts MS research group based at Queen Mary University of London (QMUL) and some of the projects that I have been involved in with

them which inspired me to start a PhD. Following this is an account of MS (which is the chronic disease that this work is centred around), this thesis' research question, aims, objectives, thesis overview, timeline of the practice-based research, ethics process and overview of the thesis' contribution.

Background to the Thesis

My interest in working within the field of MS started as a one-day placement project in 2009. This placement was part of a design brief set within the Design Interactions Department at The Royal College of Art where I was studying for my MA in design. This brief was typical of scientist–designer collaborations that came out of the course at that time which aimed at exploring the relationship between science and society through design. As part of this project, I was introduced to a research nurse from The Royal London Hospital who invited me to observe people with MS taking part in a medical research study. Later that week, I travelled out of London in a private taxi with her and a neurologist to a district hospital where people with MS were having blood samples taken in a port-a-cabin outside of the hospital building. I observed about twenty people coming in to have their blood taken. At the end of the day, I travelled with the blood samples back to the university research institute housed in an impressive, award-winning building (Figure 1). I met a scientist who took the blood samples, anonymised them, and then spun them in a centrifuge ready to start testing for the study. In one day, I observed a small snapshot of the medical research process: patients giving informed consent in the clinic, their blood sample being taken, the transport of the blood samples to the lab and the anonymisation of the samples into barcodes, as well as the routine work of the researchers in the laboratory with their technical instruments and devices. I was immediately struck by the different environments, practices and attention that surrounded the patient from those that surrounded their blood. That first day of observation led to two design projects within the MA course, followed by an offer of a research position within the Barts MS research group.

For three years, I worked as a 'Research Service Designer' at QMUL with the Barts MS research group (Figure 3).[2] My main responsibility was to improve the outpatient experience for people with MS. In this role, I had unlimited access to neurology clinics both in The Royal London Hospital and across London within other specialist neurology centres. I would routinely sit in on patient consultations next to the medical students and spend time talking to patients in the clinical trials unit as they were receiving their infusions (Figure 2).

As time went on, the projects I was involved in started producing results, and I was invited to meetings with the research team and asked to contribute to discussions

2 At the time, the group was called the Neuroimmunology Group. 'Barts MS' was created in 2014 to give the team and their work a more public-facing title. Barts MS was chosen as the team is based in Barts and The London School of Medicine and Dentistry, and the hospital is part of Barts Health NHS Trust (previously called Barts and The London NHS Trust).

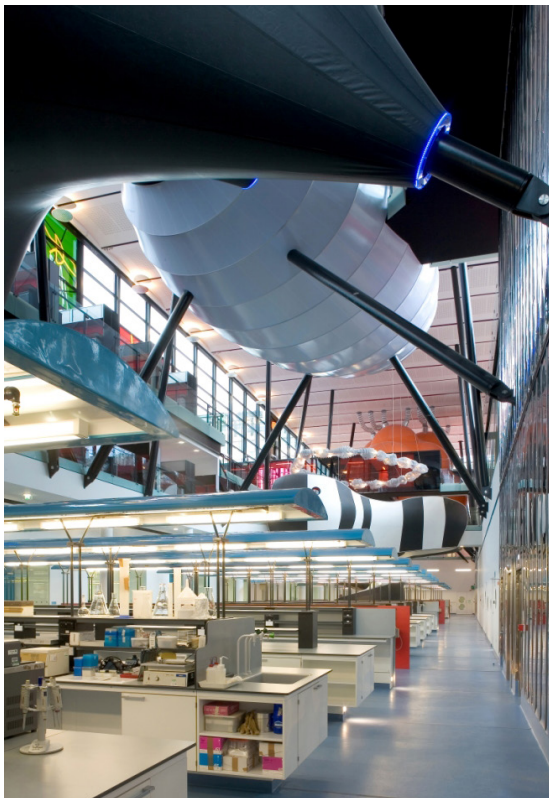


Figure 1 A photograph of the Blizard Institute part of Barts and the London school of Medicine and Dentistry at Queen Mary University of London where the Barts MS research team are based and conduct their lab based research.

Figure 2 A photograph of Ward 11D in the Royal London Hospital in Whitechapel, London where people with MS are treated by the Barts MS clinical team.

Figure 3 A photograph of the Barts MS research team (Photo credit: Dolly Clew).

that surrounded research topics and health service delivery. Eventually, I started initiating projects with the research team, and my role extended into thinking about how the patient experience could be improved through educating people with MS about current biomedical and therapeutic research. Over three years, we developed a number of public engagement projects which enabled dialogue between the research team and people with MS and their families.[3] An example of this is *Digesting Science*, an educational set of activities for children aged six to twelve with a parent with MS.[4] The main aim of the project is to teach children about MS through creative activities, but more importantly, it also works as a health intervention where families can be educated about MS prevention (Figure 4-6). Another project, *PML Risk Calculator* is a simple infographic communicating the risk of developing a potentially fatal brain infection while on an MS treatment. Through making this data clearer for patients, the pharmaceutical companies' lack of communication around informing physicians about these figures was highlighted.[5] All of these projects were unlike standard healthcare information development as this information was delivered in formats and spaces outside of routine clinical practice – mainly as weekend or evening events outside of the hospital buildings or as digital platforms.

The design perspective and methods of intervention was valued within the research group as it could highlight opportunities to design interactions between two groups of people, MS researchers and patients, who would not normally interact. The design approach also became of interest to others working in the area of patient experience: the MS charities; other departments of the university, such as the Centre for Public Engagement; and pharmaceutical companies. I was invited to speak about the projects and this approach at academic conferences (Thomson et al., 2011, 2013, 2015a) invited to become a features editor of the Elsevier journal, *Multiple Sclerosis and Related Disorders* and peer reviewer of a funding stream at the Wellcome Trust. Working as a designer within this research group allowed me to experiment with different approaches to how design could tackle the perceived disconnect between people with MS and research, with the aim of improving the information that is delivered to patients. Through this work, I developed an understanding of the limitations of using design interventions to influence the MS services delivered within the NHS. I realised the importance and the many challenges of developing designs that could fit within and impact upon the complex social, technical and institutional apparatus

3 The role of designers within the field of public engagement in science is thoroughly described elsewhere (Michael, 2011; Kerridge, 2015) and is discussed in the methodology chapter.

4 The Digesting Science project exists as a set of educational activities within five activity boxes which addresses topics of how MS affects vision, bladder function, walking, treatments and the importance of taking vitamin D. There are five kits which are circulating the UK and kits in Australia, South Africa and Israel. The project is multifaceted as events can be led by clinicians, nurses, therapists, parents, carer associations, therapy centres or charities. The project website is aimed at encouraging these audiences to access the kit and run an event for families in their geographical area ("Digesting Science," 2015). Since August 2014, there have been 63 Digesting Science events in the UK attended by 269 families and 454 children with a parent with MS.

5 The PML risk communication tool was developed originally in print in 2014, to be used in the neurology and infusion clinics at The Royal London Hospital. Since then, it has been developed into an online resource as part of the Clinic Speak project enabling healthcare professionals and patients to access up to date risk information about the Tysabri therapy (Giovannoni, 2016).

Figure 4 The Digesting Science kit

Figure 5 A family affected by MS learning about Vitamin D supplementation which has been proven to reduce their risk of developing MS.

Figure 6 A MS specilaist physiotherapist and two children with a parent with MS after completing the 'How MS affects your eye sight' activity.

of healthcare delivery. One project that was close to this took the format of a research study I developed entitled *Multiple Sclerosis Outpatient Future Groups*, which engaged patients and outpatient staff to use creative tools (Figure 7-8) to imagine improvements to the current outpatient department through engaging a future scenario (Thomson et al., 2015b). The process of planning the study to fit within the guidelines of the National Research Ethics Committee (NRES) introduced me to the many restrictions and guidelines that are in place for research within the NHS. This was an interesting process, but I became aware of the many assumptions about exactly what the research activity was and how people would be engaged and involved in the research process as either a patient or a member of staff. As a design practitioner, I felt these assumptions overlooked the located and situated interactions that actually occur between researchers, participants and other things within research events. For example, one experience from this study involved my request to take still photographs of the study participants' hands using the physical tools I had designed. My request to include this in the study was rejected by the local ethics committee as it was thought that these photographs of people's hands could still reveal the identity of the study participants. I felt that, apart from being highly unlikely, this gave a larger reflection on the issues that the committee were concerned with rather than more realistic or practical issues such as considering what the researcher will wear, i.e., something appropriately professional, or, unprofessional, or imaginative (in a previous project, I explored the potential for patients to design and make garments for their MRI scans. I demonstrated this by having an MRI scan wearing a brain lesion costume, which would be my outfit of choice if I had MS but would be considered to some as inappropriate. Therefore, I was willing to wear imaginative outfits as part of a research project [Figure 9]). This experience, along with others, and the inability at that time for me to articulate my frustration with the settings that I was working in, motivated me to start this PhD research project.

Multiple Sclerosis

A textbook description of MS describes it as 'an inflammatory disorder of the central nervous system and the most common non-traumatic cause of neurodisability in the young', (Dobson and Giovannoni, 2012, p. 1). According to the MS Society (2015), MS affects around 100,000 people in the UK. MS can be characterised by relapses, which are the result of an immune attack on the central nervous system which causes the myelin that surrounds the nerves in the brain and the spinal chord to be damaged. Historically, MS has been categorised into four groups: benign MS, relapsing remitting MS (RRMS), primary progressive MS (PPMS) and secondary progressive MS (SPMS) which describe the different relapse rates. Benign MS is very mild, and although a person can have lesions (the sign of MS myelin damage in the brain and spinal chord) on their MRI scan, they may have no symptoms. RRMS is the most common type of MS and is where relapses come and go. It can take between one week and six months to recover from a relapse, and the symptoms

Figure 8 Props (luggage tags, return ticket, passport, translation book, postcard) used to engage patients and staff to think about interactions within an ideal journey within the *MS Outpatient Future Group* study.

Figure 7 Photograph of the patient journey map created in the *MS Outpatient Future Group* study, where patients and outpatient staff came together to imagine an alternative outpatient experience using the metaphor of travelling on an ideal journey.

Figure 9 Photograph of me wearing a lesion for an MRI scan, April 2010.

can vary. The most common symptoms are optic neuritis and a pins-and-needles-like sensation in the limbs, but it can also include dizziness, imbalance and fatigue. As a person suffers from more relapses, they will recover less from these symptoms, accumulating more disability. People with RRMS will eventually develop SPMS where they do not recover from relapses and there is a gradual progression of their condition. People with PPMS do not have any distinct attacks or remissions but begin with subtle problems that slowly get worse over time.

Significant advances have been made in the past fifteen years in the development of treatments for MS. The aim of these treatments is to reduce the frequency and severity of relapses, prevent disability, relieve symptoms, prevent or delay disability arising from disease procession and promote myelin repair. Drugs used in MS treatment fall into three categories: treatment of relapse (steroids), disease modifying therapies (DMTs) or symptom relief. DMTs are used with the aim of modifying the long-term course of MS and have been found to be most effective for people with RRMS who are continuing to relapse. As yet, there is no DMT for progressive MS due to the neurodegenerative process involved. DMTs are either self-administered, meaning the patient can inject the drug or take the tablet themselves at home, or hospital administered, where the patient has to attend a hospital for infusion. The frequency of these visits depends on the treatment and can range from an infusion every four weeks to one every three months for two years.

Recent MS research, is now describing MS as one disease which operates without separate categories as they are deemed to be not supported by science (Giovannoni et al., 2017; Cerqueira et al., 2018). This argument proposes that the neurodegenerative phase of MS is present from the start of disease onset, rather than starting in the progressive stages, which would suggest that current treatments could work beyond one disease category. As almost all treatments are currently licenced for relapsing MS, the implications of this would enable people with progressive MS to access therapies and consider their MS as modifiable (Ciotti and Cross, 2018). For this to happen, clinical trials would need to firstly involve more disabled patients and outcome measures would need to be sensitive to their likelihood of change (Pardini et al., 2017). This makes the case for the need for new clinical tools to be able to measure change and improvement in more disabled patients, an important point this thesis explores further.

The Barts MS research group at QMUL is led by Professor Gavin Giovannoni. As a biomedical research group, it is at the forefront of clinical trials, re-myelinating studies and animal research in pushing the boundaries of MS research. The group consists of clinical researchers, PhD students, scientists, lab assistants, research nurses, MS nurse specialists and consultant neurologists. The group is part of UCLPartners, an initiative to bring together research groups across regional areas in London, which has access to 10,000 people with MS, about 10% of the total population of people with MS in the UK. In some respects, the group is traditional because its members conduct research, publish papers in academic

journals and present at conferences. But in others, it is innovative. Many members of this team contribute to the Barts MS Research Blog, which was set up by Giovannoni and the professor of immunology, Professor David Baker, in 2013. The blog is hugely successful and has a global readership, typically gaining over 7,000 hits per day.[6] The team uses the blog to have an open dialogue within the MS community (including people with MS, patients of the group, family members, other researchers, physicians and pharmaceutical representatives) about topical issues of the field. This includes posts on issues such as Political Speak, which discusses political issues of funding the NHS; Clinic Speak, which discusses issues from the neurology clinic and Neuro Speak, where topics are written about for other healthcare professionals. As a treatment centre, it runs a number of clinical trials, and much of the research this group produces has gone into developing treatments for people with MS currently being used today. The Barts MS research group is also open to collaboration with researchers from other fields, such as design. My ongoing collaboration with the Barts MS research group is testament to this and has continued through the process of this doctoral research.[7]

Contribution of the Thesis

This thesis aims to answer the following research question: *how can design-led research redo 'patient experience' for people with MS?* The inclusion of the word 'redoing' is key in reflecting how I propose that design-led research methods, conceived and conducted as 'performative', might enact a different version of patient experience, which I intend to be one of the main contributions of this thesis.[8] The thesis starts with these initial observations from my previous experience of working with the Barts MS research group and further investigates and examines how design-led research can rethink how patient experience is approached in both healthcare and design. In doing this, this thesis considers and works with different forms of knowledge, methods, practices and people. In the literature review, I set out a table of experience to think about how different forms of knowledge, methods, practices and people consider patient experience differently. This identifies the different assumptions that figure the 'patient' and 'patient experience' in radically different ways and shows how the different methods and techniques – and their associated rationalities – that aim to capture and measure patient experience actually produce and enact different versions of patient experience understood through the notion of performativity. This thesis aims to contribute this table of patient experience as an analytic framework to examine the relations between experience and design. The methodology used in this thesis proposes a performative understanding of patient experience, explored through practice-based, design-led research.

6 The Barts MS research blog can be accessed from http://multiple-sclerosis-research.blogspot.com/. On Wednesday the 16th September 2015, the blog received 7,046 page views. The total page views for August 2015 was 185,744.

7 The thesis was conducted part-time while I was working as a researcher as part of the Barts MS research group.

8 The hyphen has been intentionally included in the thesis title, "re-doing", to emphasis this point.

Through the remaining chapters of the thesis, I consider how the notion of performativity can help examine exactly what goes on in research events that aim to generate patient experiences. Finally, the contribution is a better understanding of the requirements of a new approach to working with an expanded notion of patient experience.

The intended audience for the thesis is multiple. Firstly, it aims to contribute to practices of involvement and engagement of 'the patient experience' in research and service development projects, such as Patient and Public Involvement (PPI) activities based in universities and NHS trusts and health service design activities within UK hospitals, making the case for the unique contribution that design-led research can bring. Secondly, it seeks to demonstrate to the design community the opportunities and practical challenges of conducting design-led research within a medical research environment with the aim of contributing to the development of design research within healthcare. Finally, it considers designers' treatment of experience and how design is deployed within healthcare practice and healthcare research. Here, I would like to contribute an expanded understanding of how designers can practically engage with healthcare professionals, patients and notions of patient experience within healthcare contexts while working without adhering to assumptions of either discipline.

Research Question

How can design-led research redo 'patient experience' for people with multiple sclerosis?

Aim

The primary aim of this research is to investigate how patient experience is created and circulated for people with MS. A secondary aim of this research is to develop a practice-based way to involve and engage people to contribute to the development of new patient experiences.

Objectives

1. Identify different versions of patient experience and understand how they are influenced by social science, healthcare practices and design.

2. Suggest ways in which design can contribute to the performativity of patient experience.

3. Deliver a research study which explores how design-led research can uncover and explore the situated enactments of MS.

Thesis Structure

This thesis consists of six chapters: introduction, literature review, methodology, pilot study, empirical research and conclusion. Below, I provide an outline of the thesis structure with descriptions of the content of each chapter.

Chapter 1: Introduction

This first chapter introduces the thesis with a description of how patient experience has become a preoccupation of healthcare commissioning (Department of Health, 2008) and introduces the growing involvement of design in this area. I also explain how I came to work in the field of MS with examples of previous work in this area, a description of MS and my relationship with the Barts MS group at QMUL.

Chapter 2: Opening the Black Box of Experience – Towards a performative understanding of patient experience

The literature review chapter sets out how researchers involved in patient experience draw upon different theoretical approaches and how this figures the patient and patient experience in radically different ways. Here, I pull out from the literature four different theoretical versions of 'patient experience'. **Experience 1** is influenced by phenomenological approaches to experience (Heidegger, 1927; Husserl, 1931; Merleau-Ponty, 1962) and can be seen in patient-subjective reports in nursing research (Crotty, 1996). **Experience 2** is a data version which, drawing on Science and Technology Studies (STS) literature, can be thought about as immutable mobiles (Latour, 1987) generated through quantitative health measurement tools such as patient-reported outcome measures (PROMs) (Walton et al., 2015) and design approaches to improve service experiences through experience-based co-design (EBCD) (Bate and Robert, 2007). Drawing on work of STS scholars, I move from understanding the production and enactment of patient experience from the register of representation to the idiom of performativity (Pickering, 1995; Law, 2004). Through doing this and including further work on performativity (Austin, 1976; Butler, 1990; Callon and Law, 1997), I set out how **Experience 3** is a performative result of the situated interplays of human, practices and objects, among others (Danholt, 2005). Finally, **Experience 4** calls for a distributed experience around the notion of an event (Fraser, 2009; Wilkie et al., 2014; Michael, 2016; Lury, 2018).

Chapter 3: A methodology for studying patient experience

This chapter describes a methodological approach to the study of multiple versions of patient experience through design-led research. The chapter starts with the methodological rationale I have chosen to use as developed from performative (Law, 2004) and inventive methods (Lury and Wakeford, 2012). This is followed by a detailed description and explanation of my choice of research methods of pilot studies and three research events

(Michael, 2016). This description includes the rationale I developed when I set out to develop a new PROM to measure upper-limb function for people with MS as a research study. It then provides an overview of the stages of the research study of three patient meetings and an online survey including reflections of the process of taking the study through Health Research Authority (HRA) approval. This chapter also includes a description of the design of these meetings as engaging situations where people, tools, and concepts come together to develop a PROM. In doing this, the chapter sets out methodological challenges and opportunities of intervening in a performative understanding of patient experience through design-led research. This highlights the limitations of current engagement and involvement methodologies of involving people in research from within the contexts of healthcare (Ives et al., 2013), social science (Lezaun, 2007) and design (Ehn, 2008), as well as outlining the ethics of working with a performative method (Danholt, 2008; Wilkie et al., 2014) with patient participants.

Chapter 4: Slowing down technologies of experience through three pilot studies

This empirical chapter reports on the three pilot studies that have been conducted as the first practice-based element of this thesis. *Consultation Pie, Willow plates* and *How far can you walk?* were all conducted between 2013 and 2015 and informed the design of the research study Measurement on Our Terms (MOT). It further describes the purpose and role of pilot studies as a research method in relation to both healthcare and design research fields. This chapter explores what kinds of technologies of experience (Ellwood, 1988) are at play in doing patient experience by introducing Stengers' notion of slowing down (2005). This enabled me to analyse experience in the making as chains of translations (Callon, 1986) and unpick specific situated practices (Mol, 2002; Suchman, 2007) and knowledges in an outpatient clinic, in a scientific conference and in a measurement activity. This chapter describes the intended aims of the pilot studies, what happened in their deployment and the learnings that each generated in my understanding of patient experience, including dealing with mess, misbehaviour, practices of simulation, working with other experience phenomena, accountabilities and assumptions of technologies of experience. The chapter concludes with an analysis of the performative effects of these studies in the contexts they are deployed.

Chapter 5: Measurement on Our Terms – A study slowing down technologies of experience

This chapter presents the Measurement on Our Terms study consisting of three patient meetings and an online survey bringing people together to share everyday hand-and-arm activities that are affected by their MS. The chapter describes what happened, how the participants interacted and responded to the research setting and the accounts they share. The activities that are discussed are considered different practices of MS (Moser and Law,

2003), or *MS ensembles*, which involve a combination of human and non-human objects with different appreciations (Pols, 2005). The top responses are gathered, discussed and reviewed against external factors aided by objects representing each activity. The chapter uses the notion of performativity to inform the analysis of how the activities were performative, the role objects had in these activities and what specific conditions affected them. Here, I look at the results of these interactions as co-productions within material environments (Pols, 2005). I explore what theoretical questions are brought up about the conditions, procedures and instruments for producing knowledge, specifically looking at how the group describes and demonstrates the limits of each activity and what it means for their daily lives. I reflect on the activities, methods, tools involved and the process of the research study to explore patient experience, reporting on the liveness of the research event where bodies, issues and research tools come together. I consider the research site and the tools that have contributed to the production of new knowledge and associated accountability of this from the expertise of people with MS and their situated actions of living with MS (Callon and Rabeharisoa, 2004). At the end of this chapter, I describe my realization that doing a PROM that could simultaneously capture *experience ensembles* and be scalable is misguided, if not impossible. Instead, I discover that a new form of experience technology is required which is beyond the scope of this thesis, so I speculate about what this would look like and how it would exist. Finally, the chapter points to two directions as future possibilities for a new technology of experience, while outlining the practical contingencies of doing this type of work through practice-based design research within the NHS.

Chapter 6: Conclusions

This final chapter summarises the research findings and clearly articulates how the contributions of this thesis sits within understandings of healthcare, social science and design-led research. I reflect on the ways and degrees to which I have addressed my research question and how the research has contributed to the development of my design research practice and the opportunities it has provided me for further research. I conclude this section, and the thesis, with implications for future research in this area, reflecting on the contribution this research makes to current practices of patient experience in design, healthcare and social science, as well as future developments in areas such as patient engagement and involvement practices where the research may be further relevant.

Accountabilities and Ethics

One of the challenges of writing this thesis has been framing the work amongst different fields of research and practice. As I have already pointed out, there are multiple audiences for this work – designers, healthcare professionals, MS researchers and those involved in patient engagement and involvement - each with different academic traditions and accountabilities linked to them. Therefore, I am accountable to different audiences. For

the practice based and theoretical contributions of this thesis to speak to these multiple audiences, it must not only meet, but stand on the same ground as them. The substantial appendix to this thesis demonstrates the level of transparency required in the health research process by presenting the number of regulatory documents involved in this work. I include these to clearly show that the research has been conducted according to ethical guidance in healthcare but also in part to demonstrate the amount of commitment, application and extended work involved to involve patients in research processes with design research. For audiences that are not accustomed to this process, the illustration in Figure 10 demonstrates the timeline of how I completed and successfully gained QMUL ethics, NRES ethics and HRA approval for the Measurement on Our Terms study.

Presentations, Workshops and Lectures Conducted Related to PHD

Throughout the duration of the PhD, I took part in a number of initiatives specific to this research, enabling me to present my work to a range of design, social science and medical audiences at different points in the research process. These are listed on page 33 and became incredibly productive moments as they enabled me to not only organise my thoughts at that time into a coherent presentation but also to gather feedback and responses on my research direction and thinking.

Intended Future Outputs

The intention is for this research to be disseminated in many different formats to different areas. The practice-based work is ongoing in that it continues to contribute to conceptions of a new technology of experience that will enable people with MS to measure their upper-limb function. At the moment, this involves the *Under and Over* project, which is briefly introduced in chapter 5. This will be shared and distributed across the patient community through the Barts MS research blog and the Barts MS and UCLP clinical services. It can also take on more participatory approaches of dissemination at patient events, such as *MS Life*, a bi-annual event attended by around 5,000 people with MS organised by the UK MS Society and *MS Research Days*, annual events attended by 350 people with MS organised by the Barts MS research team. The sustainment of this project will also contribute to the PPI and public engagement academic community at QMUL and wider where different results, insights and further research will go on to create more knowledge about the process of patient experience exploration.

The more theoretical aspects of the research, such as the table of experience and writing on how performative design-led research can explore patient experience, will be disseminated through academic papers aimed at researchers interested in healthcare research, design and STS. The hope is this will also be presented at relevant design research conferences, such as the *Design Research Society, Design 4 Health, Include*, and *Research*

Through Design, to communicate effectively the value of this thesis' contribution to the design research community.

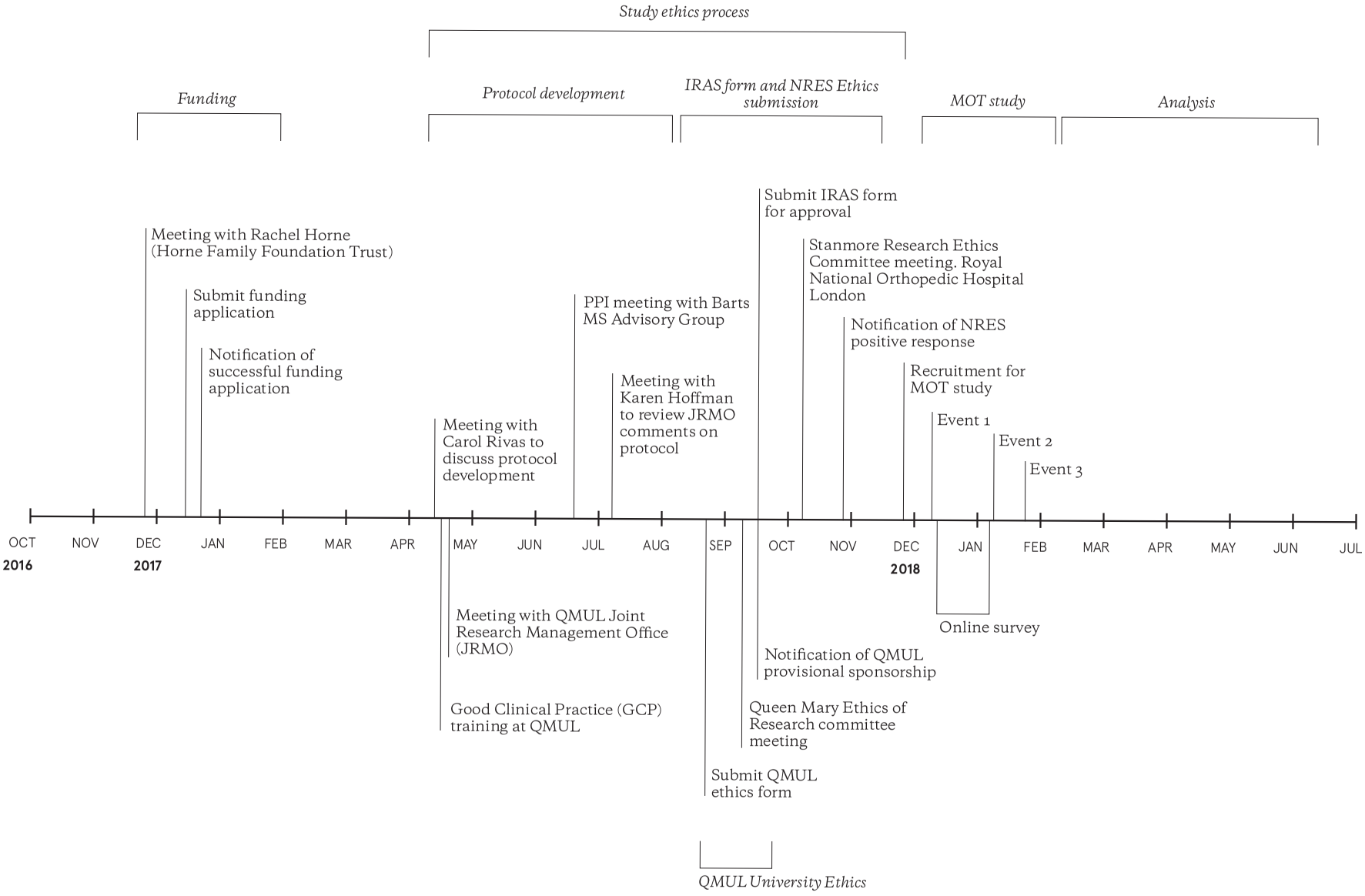


Figure 10 Timeline of the MOT study development and ethics process.

PRESENTATIONS, WORKSHOPS AND LECTURES CONDUCTED RELATED TO PHD RESEARCH

2013 Interviewed by Leah Armstrong, for the Arts and Humanities Research Council project, *Mapping Social Design*, 4th December

2014 Lancaster University PhD Summer School presentation: *Re-doing patient experience through design-led research: considering the multiplicity and ontological politics of MS*. Lancaster University. 30th June - 1st July

2015 Panel discussion: Design Culture Salon 15: *How does design address immobilities in our society?* V&A Design Culture Salon, 13th March

Research Presentation: *Speculation as Design Research*, Goldsmiths Design Festival, 2nd September

Research Presentation: *Re-doing the Patient Experience for people with MS*. Doctoral Research in Design, part of Goldsmiths Design Festival 3rd September

CSISP Salon. *Measures of/for health: Practices and instruments*. Co-organised with Vera Ehrenstein, 18th November, Goldsmiths

2016 Take part in Patient Engagement Steering Group, Wellcome Trust, January – September

2017 Lecture to medical students: *How design-research can re-do the patient experience*, Complex Healthcare Processes Research Group, University of Southampton, 7th March

Lecture to MSc students: *How design-research can re-do the patient experience.* Anthropologies of Global Health Lecture to MSc Global Health Modules QMUL, 9th March

Research Presentation: *Speculation as Design Research*. Design Matters PhD forum, Department of Design Goldsmiths, 13th April

Research Presentation: *Speculation as Design Research*. Research Matters, Barts Health NHS Trust, 24th May

Research Presentation: *Speculation as Design Research. What matters to you?*, Patient Experience conference, Barts Health NHS Trust, 12th July

2018 Contribution to Design for Health(care) track at DRS2018, University of Limerick, 25th – 28th June

Participate in Nordes summer school, *Design and Care*, Linnaeus university Växjö, Sweden, 14th – 17th August

Chapter 2: Opening the Black Box of Experience – Towards a Performative Understanding of Patient Experience

This literature review will explore how 'patient experience' variously operates in healthcare and design by drawing on literature from philosophy and the social sciences. Patient experience is a phrase frequently used in research involving patients and health interactions which can be traced through diverse fields of literature. Therefore, it is important to be clear about the trajectory that I take through these different research disciplines to include and exclude different ideas and references to notions of 'patient experience'. There is a large body of qualitative research from the sociology and anthropology of health and illness that focuses on capturing and theorising different aspects of the patient experience, arguing importantly that it extends well beyond the clinical context, the body and its relationship to society and the patient themselves. For example, scholars such as Strauss' work on chronic illness expands understandings of illness as work conducted at home (1975). Reviews of 'lay' experiences of health and illness trace the 'missing voices' in historical accounts of patients life-worlds in medical sociology and point towards more interdisciplinary research (Lawton, 2003). More recently, there has been increased sociological attention that is critical of the way in which the patient experience is framed and incorporated in health policy, research and practice specifically looking at participation in healthcare (Rabeharisoa, Moreira and Akrich, 2014) and a more health services research approach to the problematic operationalisation of patient experiences (Martin, 2008; Martin, Carter and Dent, 2018).

The focus of this thesis, however, is on how the patient experience has been specifically deployed within clinical and scientific research settings rather than within the social sciences more widely. Empirically, my approach is distinct from studies of patient experience from sites of patients' homes or workplaces, to focus on particular situations within clinical interactions, scientific dissemination and measurement activities. The broad field of potentially relevant literature has been delineated for the purposes of this thesis by staying close to how 'patient experience' has been predominantly understood in research and participatory activities in healthcare, and then goes on to draw on ANT inspired research that emphasises performativity to rethink this. This specific trajectory has been further influenced and guided from the forms of sociology encouraged from the sociology community at Goldsmiths where this research is also closely linked.

Patient experience is also considered from embodied perspectives of disability studies in relation to equality and social inclusion. Again, this broad field of study encompasses a range of medical social scientific and rehabilitative disciplines (Bury, 1991; Williams, 1999; Barnes, Oliver and Barton, 2002) as well as the perspectives of disabled activists (Oliver, 1990; Shakespeare and Watson, 2001). Thus, though I briefly reference work at the intersections of STS and disability studies later in the thesis, the wider area of literature is not heavily drawn on. I am conscious that looking to this broader field would provide a further source of inspiration for thinking about the generative MS ensembles and technologies of experience that I set out later in the thesis. Although both sets of literature provide interesting and promising accounts of patient experience, it is beyond the scope

of this thesis to fully incorporate those literatures. These would be interesting directions for future research. Therefore, the literature included in this chapter focuses on the use of design thinking and practices as a means for rethinking and redoing patient experience in the context of primarily clinically orientated MS research and care.

This literature review chapter is organised around four versions of 'experience' as understood and practiced across a range of different fields. The aim here is to identify how these are mobilised in and enacted through practice and highlight the different assumptions inherent in these approaches. The first understanding of patient experience will start with a brief outline of the theoretical tradition of experience, drawing on particular philosophical perspectives. The second understanding will go on to review approaches to measure and capture patient experience within clinical and design practice. This will establish both qualitative and quantitative approaches to measurement as technologies of experience. The third understanding will introduce the notion of performativity as an analytic lens to further examine the patient experience and unpick exactly what these technologies of experience are doing. The fourth, and final, understanding will examine how the notion of an 'event' can contribute to thinking about how patient experience is brought about and the 'felicity conditions' that are required in its enactment. This chapter will conclude with some considerations for a performative understanding of patient experience and consider how this will inform the methodology chapter. Figure 18 on page 68, at the end of this chapter, presents these different understandings of patient experience alongside one another. Throughout this review, I will draw on empirical examples of patient experience from my research with the Barts MS research team to illustrate this analysis.

Experience 1: Subjective Approaches to Experience

To help follow my indexing of the different understandings of experience, and to help me in this discussion, I bookmark each new definition in the format of an indented box and **change of font** as I introduce and refer back to it. This allows me to compare and contrast different types of 'experience' in Figure 18 later in the thesis.

> **Experience 1: This first understanding of experience is of a patient's inner, subjective experience of events of which they have a first-hand experience. This understanding is heavily influenced by phenomenology and is dominant in healthcare practices that treat patients as subjective beings.**

In this section, I introduce **Experience 1** starting with the various philosophical perspectives that are drawn upon and frequently referred to when explaining this version of experience. The reason for this starting point is that philosophical perspectives underpin and inform different approaches to experience within healthcare, and as I go on to point out, are similar to how designers approach experience within service improvement projects. This

is followed by a discussion on the assumptions that are inherit in the main understandings of lived experience – phenomenology. I will then draw on literature in STS to unpack the assumptions inherit in both medicine's and design's approaches to patient subjectivity.

The experience of thinking, acting and existing in the world is thought about and underwritten by different philosophical perspectives. Much of this can be traced back to the eighteenth century, when the approach to philosophy by David Hume, and before him John Locke, argued for experience-based thinking where nothing is knowable without experiencing it first in the physical world. This is called 'empiricism', which states that all knowledge comes from sensory experience – what we can see, touch and smell – and this is the only knowledge people can have. In other words, we can only know something through having had a sensory experience of it. It is through empiricism, and its further development into positivism, that the scientific method is logical. Positivism, coined by Auguste Comte, goes further than empiricism to argue that for this knowledge to be authentic, it has to be created through specific methods with logical principles – the scientific method. This scientific and logical treatment of sensory experience enforces principles to ensure authentic knowledge is produced. These principles are applied to sensory experiences through conducting experiments that produce results that can then be interpreted. Shapin and Schaffer (1985, p. 25) argue that experiments, or what was established as the experimental and dominant scientific mode of empiricism by Robert Boyle, include three key aspects: First, the exact apparatus pieces that are used to conduct experiments. Second, experiments and scientific procedures are to be carried out and documented in a specific way (e.g., documenting through writing in descriptive language and using intricate diagrams). Finally, repeating experiments and exploring if different or unintended results are produced. Here, a person witnessing an experiment is not enough to gain consensus of a result, it has to be repeated for and by others. The reliability of experiment results and the removal of individual bias – objectivity – is key to the scientific method.

Both empiricism and positivism treat sensory experience in this way, which is a very different approach to considering the inner, personal experience of a person. This is described as the lived experience, and it is the relationship between how people experience things as humans and the meanings things have in their experiences. This would describe experiences that people have as a phenomenal experience. This is different from how empiricists treat experience; they would try to determine the experience's meaning through third-person reliability and downplay any first-person interpretation. However, the study of phenomena argues that people ascribe meaning to every event as a mental construct that is unique for each person.

Since the nineteenth century, positivist thinking about experience dominated social and behavioural research where approaches to health research was based on numerical measurement and were generally quantitative research methods. But in the 1980s and 1990s, the use of qualitative methods in healthcare research grew rapidly through a

rejection of this positivist paradigm within academic research (Morse, 1991; Smith, 1992; Nurse-Patient Relations and Benner, 1994; Greenhalgh and Hurwitz, 1998; Reiners, 2012). Influential articles in prominent journals such as the *British Medical Journal* called for more relevant, achievable and appropriate qualitative approaches to produce knowledge about patients' experiences, feelings and emotions than that of the currently dominant quantitative methods (Mays and Pope, 1996). This research, and considering people's phenomenal experiences being located in the human mind, went on to produce certain views of human subjectivity and patient experience that were taken up in healthcare, which I will now go on to explain.

Phenomenology and Experience

The study of phenomena, phenomenology, is the dominant theory of experience within philosophy and is closely associated with the work of German philosopher Edmund Husserl and his student Martin Heidegger. It is based on the premise that reality is what is perceived or understood in human consciousness. There are essential differences between Husserlian and Heideggerian phenomenology, which can be illustrated in how it has been taken up in nursing research to try to better understand human behaviour in health and illness research. Following Husserl (1931), the nursing approach to understanding patient experience considers the patient's direct awareness of an event. Here, a researcher might conduct an interview with a patient to study the patient's description of their perception of an outpatient clinic. This is a descriptive approach to access the phenomena of experience concerned with epistemological issues of the basis of human knowledge, where people are detached subjects in a world of objects. Husserlian phenomenology retains the Cartesian object–subject divide. However, Heidegger (1927) reacted against this and argued that not everything is a product of consciousness (e.g., the feeling of anxiety and dread [Walters, 1995]). Heidegger's work is interested in more ontological issues and concepts of being in the world over knowing the world (Reiners, 2012). This is an interpretive approach based on existential perspectives which proposes that an understanding of the person cannot occur in isolation from that person's world. Therefore, a researcher might ask a patient to complete a diary about their outpatient clinic experience to better understand the interpretation of their experience of being in a clinic. Although both of these approaches to experience have been taken up by nursing researchers, much of this work fails to differentiate between the different epistemological and ontological focusses which have different implications for research methodologies (Walters, 1995, p. 791).[1]

Later developments in phenomenology went on to conceptualise the role of the body in how we experience, introducing the idea of embodied knowledge. Maurice Merleau-

1 This is also the criticism of Michael Crotty who in his book, *Phenomenology and Nursing Research,* argues that the research conducted by nurses using phenomenology actually developed a North American hybrid of the philosophy. See Crotty (1996).

Ponty's (1962) work considers health and illness as an embodied experience that we have a position of, from within a body that we are perceiving the world through. Merleau-Ponty calls this the lived body, and this is something separate from the objective body. The objective body is that which medicine treats and the lived body is how we experience our body. He argues that in first-hand experience of living day-to-day as a healthy person, we do not notice the difference between the objective body and the lived body. It is only when we are ill or something goes wrong (e.g., we experience symptoms, pull a calf muscle when running or get a headache) that the objective body is brought to our attention, and we start to notice our body. So this approach to experience would argue that two people can be affected by the same thing, but because they have different bodies, it will affect them differently. Phenomenology places an important role on humans' ability to perceive the world, stating that perceived experience is the foundation of subjectivity (Merleau-Ponty, 1962, p. 146).

Assumption 1: Limitation of Perception

I have started to unpack some of the main philosophical approaches to experience. This has highlighted two key assumptions that underpin **Experience 1**. The first assumption is how phenomenology deals with the subjective perspectives of individual people and can be described as the limitation of perception. Havi Carel (2012) effectively uses the example of a native English speaker and a non-native English speaker hearing the same sentence in English. They hear the same sentence but perceive it differently due to their different perspectives of the world. Relating this to health, the experience of living with a chronic illness is different for everyone. For people living without the illness, the experience may look awful, but in fact, the experience of living with illness may be very different from what it is perceived to be. This critique on perception is also articulated by scholars of disability studies who argue that if we are not experiencing the same events through the same body, then we have no way of really grasping or understanding the embodied experience (Diedrich, 2005; Moser, 2006; Galis, 2011).

This assumption impacts how patient experience is thought about and approached in healthcare practice, research and policy. Within the NHS, it is widely understood that allowing patients to report on their experiences of care is key to understanding their experiences, as supported by departments such as The King's Fund (Goodrich and Cornwell, 2008). Within the Barts MS research team, patients talk about their experience of living with MS frequently. They run a three-day MS preceptorship teaching course where trainee neurologists, clinical nurse specialists and pharmaceutical representatives learn about MS treatments and care. The teaching course includes eight, thirty-minute sessions where patients share their experiences of issues such as pregnancy and MS, pain in MS, diagnosis, sphincter dysfunction, cognitive impairment and treatments. This is widely regarded as the most popular component of this course. In this situation, individual patients

become representatives or spokespersons (Callon, 1986, p. 13) speaking on behalf of others, not just for their own experience but for 'the patient experience', representing a wider population of patients (Collins and Evans, 2002).

This assumption within **Experience 1** has further problems for accessing and reporting experiences. Phenomenology places experience in the minds of individual people, which presumes that an individual's mind is the centre of and cause for their experience. So then, the only way for others (in the case of this thesis, neurologists, researchers or designers) to access this experience is through the experiencing person reporting on it. In other words, as a person experiences an event, they interpret it, and it goes into that person's memory. As time passes, other memories join it. When that person then reports on that event, a description of the memory is reported. This is described as 'the problem' (Chalmers, 1995, p. 200) of subjectivity. As a source of knowledge, subjective experiences are unreliable as they are affected by that person's perspective of the world (their ontological view) when going in and out of our memory (Dennett, 1991). So then, when we recall an experience, we re-experience it in our minds. This is unlike empiricism and scientific experiments, where a third person can verify or falsify a result; it is not possible to separate the event from the person's viewpoint and see another person's raw data to compare the actual event with the report of the event itself.[2]

Design and Experience

The phenomenological understanding of experience and the limitations of perception highlight interesting aspects of how experience has become a key operator in design. Different genres of design have responded to the notion of experience as a hitherto untapped and underdeveloped resource. The field of experience design (Shedroff, 2001; Benz, 2015; Wendt, 2015) focusses on the design of experiences as an aspect of consumption since the rise of the experience economy (Pine and Gilmore, 1999). This distinct historical stage of economic development in the 1980s saw an extension of consumer culture where global companies and brands such as Starbucks and Disney operated by way of staging or 'theming' (Lury, 2009, p. 75) experiences that provided particular sensations for people as customers and, in more recent work, addressing them as audiences (Ben Hayoun, 2017). Bill Moggridge (2007), co-founder of IDEO, one of the world's largest design companies at that time, described how experiences emerge in the interaction of objects, interactions, spaces and information, transcending different mediums (Svabo and Shanks, 2015, p. 26). Lury (2009) goes on to describe these complex relations between consumer and brand as *assemblages* to reflect the diverse practices, technologies and mediums that are involved

2 The notion of `raw data' is contested (Räsänen and Nyce, 2013) as the term was used by Swedish intelligence practitioners who were interested in challenging these common sense understandings of key terms like raw and cooked. They described how `data' is already shaped and full of assumptions prior to being analysed – so `raw' data rarely exists, if at all.

in the processes of branding. This approach of companies and designers working in this way to generate experiences for customers or audiences is described as a first-generation understanding of the experience economy in design. In this, people are reduced to passive targets who generate experiences as an automatic response to design (Strandvad and Pedersen, 2015, p. 108). But, beyond identifying that some form of value is created for people as customers, consumers or audiences, there is no more clarity on what an experience is according to this generation.

A second-generation understanding of the development of the experience economy in design focusses on customers' sensory perceptions, the creation of meaning and the process of co-creation (Prahalad and Ramaswamy, 2004; Boswijk et al., 2007). This understanding along with the growing focus and study of *users* (Bjerknes et al., 1987; Suchman et al., 2002a; Wilkie, 2010) from within fields such as user-centred design (Norman and Drapper, 1986) made people who were capable of experiencing, central to design activity.[3] Users became a central focus of design due to the influence of the Scandinavian design tradition. This influence was the result of union-supported projects introducing new workplace technology in Norway in the 1970s, which has since become internationally known as Scandinavian participatory design (PD). Here, users were invited to co-operate through the entire process of design, involving people to contribute their perceptions (and experiences) and taking their 'work practices seriously' (Greenbaum and Kyng, 1991, p. 15) in the design activity. The researcher wanted to empower the workers whose jobs would be otherwise replaced by the new technology (Ehn, 1989). This Marxist-inspired approach enacts democratic principles by inviting the end users of a design (the people who would be affected by the change, the workers) to co-operate in the entire process of design.

In the context of healthcare, over the past decade, there has been an emergence of PD-inspired approaches of co-design (Sanders and Stappers, 2008), co-creation (Cottam and Leadbeater, 2004) and co-production (Boyle and Harris, 2009) to consider the user as a central focus and active member of the design activity (Pullin, 2013; Donetto et al., 2015). Currently, the most successful approach to improve the patient experience of health services is experience-based co-design (EBCD) (Bate and Robert, 2006), which is deployed by the NHS Institute for Innovation and Improvement to allow staff, patients and carers to reflect on their experiences of a service and work together to identify improvement activities

3 I use the term user-centred design as a generic term to broadly describe approaches to design that consider user involvement and use contexts as essential of the design process. This includes Participatory Design (PD) (Greenbaum and Kyng, 1991; Schuler and Namioka, 1993; Kensing et al., 1998) and Human Computer Interaction (HCI) (Norman and Drapper, 1986) although I understand that these have different methods, practices and have been developed in relation to different theories. For example, early PD work was inspired by Marxist and Wittgenstein theoretical models of democraticisation and more recently interested in ANT (Callon, 2015), whereas HCI was interested in cognitive psychology concerning human factors, cognition and embodiment to think about human interaction with technology.

(Figure 11). It is then up to this same group of people to devise and implement changes and then reflect on their achievements.[4]

> EBD is a user-focused design process with the goal of making user experience accessible to the designers, to allow them to conceive of designing experiences rather than designing services. (Bate and Robert, 2006, p. 309)

The reference to the user in the quote above is typical of the EBCD approach for experience, as well as the design literature around experience design more broadly. It highlights the assumption of **Experience 1**, where design deals with experience as a pre-existing subject that is stored in someone's mind. The EBCD approach assumes that patients have access to their inner experience, the introspective event, which they can report on (Hollway and Jefferson, 2000), and in doing this makes assumptions that we can access our own inner experiences and know them (Henriques et al., 1998). If a designer wants to understand it then, they ask the person to report on it. Ultimately, once a designer can identify and grasp an experience, they can change it (Shedroff, 2001; Cain, 2010).

Participatory approaches in design, such as EBCD, attempt to remove the limitation of perception by involving people who will be part of the end change or service in the improvement activity to contribute their individual, subjective experiences to the design process (Pullin, 2013). But, this does not account for the reporting of experience being problematic, as everyone's ontological view is different. Further, in approaches such as EBCD, it is important to not overlook PD's original strong political agenda in workplace democracy. Due to this agenda, the reason for engaging these potential users within the design process is not only to make better products and systems but also to consider the social and ethical implications of a new design. In other words, organisations have many motivations for initiating these projects other than solely creating new patient experiences. For example, in a review of current EBCD projects, patients reported feeling like outsiders during the decision-making process, and staff referred to external locus of control (Bowen et al., 2013, p. 242) giving rise to particular configurations of power in both co-design activities and the implementation of change.

4 EBCD was originally developed from experience-based design (EBD). EBD was advocated by Cain (2010) for product development then further applied to a healthcare service improvement context by design company IDEO (Freire and Sangiorgi, 2010). A typical EBCD cycle would take between 9 and 12 months with six stages: (1) project set up, (2) gather staff experiences of the service through observations and interviews, (3) gather patient and carer experiences through observations and filmed interviews, (4) bring staff and patients together to watch a 'trigger' film of patient narratives to identify priorities to change, (5) co-design work in groups of 4-6 around these priorities, (6) have a celebration and review event. See Bate and Robert (2007).

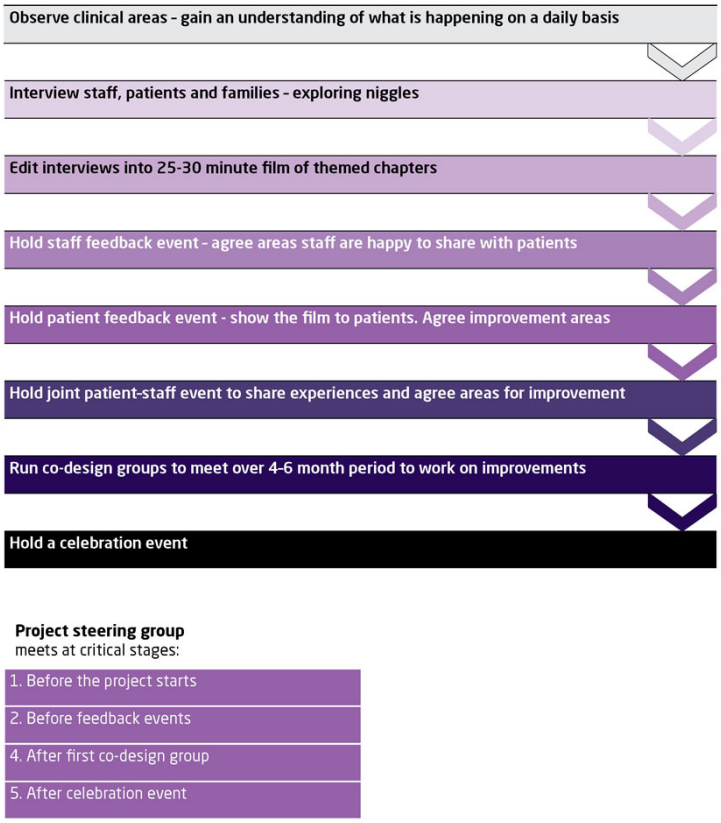


Figure 11 Stages in experience-based co-design as described on The Point of Care Foundation website where healthcare staff can access the EBCD approach toolkit (Source: The King's Fund (2018). Stages in experience-based co-design. [image] Available at: https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/step-by-step-guide/1-experience-based-co-design/ [Accessed 27 Dec. 2014]).

Assumption 2: STS and Experience

The second assumption of the phenomenological understanding of experience is that it prioritises the human perspective and perceiving subject above all others. John Searle (2008) describes how the phenomenological perspective is limited by saying that if something is not perceived to be present, then it is not real, meaning it only considers phenomenon that can be seen or experienced through human senses. Although Searle is referring to the limits of the ontology of phenomenology – what it considers to be real – the limitation of solely considering humans and human perception is also a criticism of the construction of scientific knowledge from STS.

STS is a field that has been preoccupied with the epistemic practices of scientists since the sociology of scientific knowledge (SSK) (Bloor, 1976; Barnes, 1983; Collins, 1983).[5] SSK challenged the historical dominance of the philosophy of science by questioning the production of scientific knowledge and knowledge claims. Laboratory studies were foundational to the development of STS as a response to SSK (Knorr-Cetina, 1981; Latour and Woolgar, 1986) where sociologists and anthropologists conducted ethnographic fieldwork, observing and following scientists in their natural – laboratory – settings, 'in action' (Latour, 1987, p. 59), to determine its qualities and attributes. Laboratory studies argue that knowledge can be studied through how it is produced and the material practices, objects and situations that are involved in creating it. Actor network theory (ANT), an approach within STS, grew out of laboratory studies, notably the work of Michel Callon, John Law and Bruno Latour, further developing the preoccupation with the empirical analysis of material practices.[6]

Somewhat notoriously, ANT includes the view that human and non-human actants should be treated symmetrically, or analytically equal (Callon, 1986; Latour, 1987).[7] This is similar to Callon's (1986, p. 200) writing about *free-association*, where both society and nature need to be considered without a priori distinctions between them. ANT describes human and non-human *actants* (as the term *actor* is most likely to talk about the roles of humans) with the same language and gives them an equal amount of agency. Actants have the power to act and are tied in chains of association which construct networks of humans and non-humans. Through these actor networks, human and non-human entities emerge,

5 Thomas Kuhn's *The Structure of Scientific Revolutions* (1969) energised a new discussion about science which opened up a space for factors other than scientific method and truth to be considered in the contractions of scientific facts and reality. David Bloor (1976), along with Barry Barnes (1983), was influenced by the sociology of science and developed the strong programme in the SSK. The strong programme set out to provide sociological accounts of scientific knowledge and went on to have huge influence on STS.

6 The field of STS includes many different approaches - SSK, Laboratory Studies, Social Construction of Technology, feminist approaches and ANT history of science.

7 The notion of symmetry was developed by Bloor and Barns is around explaining truth claims of knowledge. This is also described as a 'Whig' history (Law, 2004), where past scientific knowledge contributes to current facts. So, for example, if a scientist is conducting an experiment and it comes back positive, they are creating knowledge and can claim that knowledge to be true and scientifically sound within their experiment. They can do this without having to go back and re-prove the previous facts their experiments are based on because they are also considered true through scientific method. However, if previous knowledge does not fit with current ideas, then it needs to be explained. This is described as an asymmetrical explanation, as true and false knowledge are explained in different ways.

interact and produce effects such as the loss of leg function for a person with MS (Moser, 2000, p. 205). These networks are not pre-determined or absolute, but their identity is defined through their interaction with others. For ANT scholars, the relationship between all actants is under investigation. This is to say that it is how networks of actors act that defines what they are. Callon (1986) demonstrates this in his study of fishermen in Saint Brieuc Bay when he describes how, in the process of translation, both non-humans (the scallops) and humans (the fishermen and scientists) are being ordered and defined. Latour, a key proponent of ANT, directly criticises phenomenology for endorsing the concreteness of humans and for being unable to consider other, non-human objects having agency (or being capable of having experience).[8] Crucially, and in contrast to phenomenology, ANT can offer another understanding of patient experience that does not pre-suppose a model of the patient as being a subjective figure.[9]

Including STS literature and using an approach that draws on ANT not only enables me to unpack the assumptions within the ways that patient experience is currently enacted in healthcare and design (e.g., **Experience 1**), but it is also be an extremely effective tool for describing the processes by which patient experiences come into being, or fail to materialise. But in doing this, I need to be aware of theoretical and methodological debates surrounding the concept of non-human agency, some of which I describe here. Firstly, the implications of non-human agency is widely disputed as it is argued that humans and non-humans should not be given equal power in the network as humans have intentionality (Collins and Yearley, 1992; Winner, 1993; Bloor, 1999).[10] Latour (1992) responds to this anthropomorphism criticism – that of attributing human characteristics onto non-humans and objects – by saying that ANT treats all entities as having agency, but not human properties. Secondly, ANT has been criticised as describing accounts of agency as heroic (Star and Griesemer, 1989, p. 390) with its privileging of certain heterogeneity over others. In a network of heterogeneous actors, Star (1995) argues that the framing of these accounts is told from the point of view of the human – the scientist or the researcher – rather than the lab technician or the test tube, for example. Finally, there is the 'god trick' of viewing the world from everywhere and nowhere (Haraway, 1991, p. 189). This is in regards to how the researcher traces the networks without accounting for their own participation and potential influence. Regardless of these well-known criticisms, including Latour's (1999), which deals with ANT's central meaning, it is still an effective tool for rethinking ideas

8 Latour's account of understanding experience is influenced from Stenger's reading of Alfred Whitehead and his influence from William James, who gives an account of experience that is full of individuals more abstract than that of actors (Latour, 2005).

9 Varela (1999, p. 331) discusses further work being done around the scientific studies of consciousness, which is also suspicious of subjective experience. Here, research aims to revise the manner in which accounts of human experience have to be approached in empirical research.

10 ANT's notion of generalised symmetry is a form of radical symmetry which is more extreme than was previously developed by SKK scholars Bloor (1976) and Barnes (1983), and does not come without criticism.

that have been taken for granted, like **Experience 1**, that are problematised through ANT.[11] STS, and more specifically ANT, provides me with analytical tools through which to take apart phenomenologist understandings of patient experience and **Experience 1**, and can help explain how experience is produced and how it travels within healthcare.

Experience 2: Patient Experience Data

> **Experience 2: This version understands patient experience as a measured and objective phenomenon such as a number or a measure produced through data as generated from and reported through patients' subjective accounts. This version can travel and have agency in making subjects, and it is an immutable mobile. It is reduced into numbers and icons through quantitative tools and diagrams. This is not to be confused with the phenomenological perspective of experience which is the inner experience of a person, this notion is a generalised data version.**

In this section, I will discuss the second understanding of patient experience, **Experience 2**, where patient experience is accessed through quantitative measurement tools within clinical practice and reduced to diagrams in design activities. I will describe how different versions of patient experience are figured through these tools and describe the theoretical perspective underpinning their use.

Over the last decade, there has been a steady increase in efforts to gather data about patient experience to improve service quality (Wolf et al., 2014) while being used to get a better understanding of a patient's quality of life. Health-related quality of life (HRQoL) is 'the patient subjective perception of the impact of his disease and its treatment(s) on his daily life, physical, psychological and social functioning and well-being,' (Riazi, 2006, p. 93) and is gathered through a combination of questions which asks patients about different aspects of health and about how this affects their lives. Patient-recorded outcome measures (PROMs) are the research tools used to record and compile this data, and take the form of questionnaires and interviews designed to determine the patient experience. Health-rating scales, such as PROMs, are measurement instruments that aim to quantify characteristics of people that cannot be directly measured (like height and weight) (Hobart and Cano, 2009, p. 7). They are said to 'gain meaningful subjective accounts from those receiving care,' (Jenkinson and Fitzpatrick, 2013, p. 72) as they are completed by patients themselves. For example, the MSQOL-54 (Vickrey et al., 1995) includes questions to determine the HRQoL,

11 I have attempted to be reflexive in my account of patient experience by including an upfront description of my involvement with the research context in the Introduction chapter. This is further addressed in the methodology chapter.

such as 'In general, would you say your health is,' with the option for the patient to respond with 'Excellent, Very good, Good, Fair and Poor'.

The medical community considers these paper-based tools to be new because the patient is at the centre of the evaluation activity; however, they are still used in conjunction with physician-based measurement tools to supplement more biomedical-defined outcomes. In MS care, PROMs are used to record the impact of the disease and treatment from the patient's perspective and are used alongside physician- or clinical-based outcomes, such as magnetic-resonance imaging (MRI) scans, relapse rates (Riazi, 2006) or Expanded Disability Status Scale (EDSS) scores. In MS, many PROMs have been developed or repurposed to create a more complete picture of the patient experience of living with MS.[12] Examples include: MS Quality of Life 54 (Vickrey et al., 1995), Functional Assessment of MS (Cella et al., 1996), MS Quality of Life Inventory (Ritvo et al., 1997), Multiple Sclerosis Impact Scale (MSIS-29) (Hobart, 2001), MS Functional Composite (Fischer et al., 1999), UK Neurological Disability Scale (Sharrack and Hughes, 1997), MS Quality of Life Index (LaRocca et al., 1996), the Leeds MS Quality of Life (Ford et al., 2001) and the Health Related QoL for MS (Pfennings et al., 2009).

Within MS, PROMs are used as clinical outcome assessments to measure the efficacy of treatments in clinical trials (Walton et al., 2015). The importance of choosing the correct clinical outcome assessment for trials was recently discussed in the results of the ASCEND trial, where for the overall population of patients made up of people with RRMS and SPMS; the results of the trial were reported as negative (Giovannoni, 2014, 2015; Kapoor et al., 2018).[13] Yet, for people with SPMS involved in the trial, participants reported and showed signs of improved upper-body ability, but this was not reflected in the trial results because the PROM that measured the clinical outcome assessment was not sensitive to measure this improvement. The choice of PROM to report this then came under scrutiny, as it did not reflect this result.[14]

To have a better understanding of how these tools produce patient experience data and what assumptions of experience they draw on, it is necessary to have a closer look at how the tools are developed. One of the most widely used PROMs in MS is the MSIS-29

12 Some outcome measures have been developed in one condition, such as stroke, and then used in another. This is a point of debate within the measurement field (Hobart et al., 2005) as although the original tool provided considerable evidence for validity in a variety of populations including MS, (Vickrey et al., 1995), later publications have disproven this with the inclusion of psychometric measures. 'Psychometric limitations of the SF-36 in multiple sclerosis include significant floor and ceiling effects (Freeman et al., 2000), limited responsiveness (Freeman et al., 2000), underestimation of mental health problems (Nortvedt et al., 2000) and a failure to satisfy assumptions about scaling summary scores (Freeman et al., 2000)', (Hobart, 2001, p. 963).

13 The ASCEND trial was a clinical study on the Efficacy of Natalizumab on Reducing Disability Progression in Participants with Secondary Progressive Multiple Sclerosis.

14 The clinical outcome assessment for the ASCEND trial was the 25-foot times walk and 9-hole peg test. People with SPMS are likely to suffer severely from mobility problems, which would not likely be improved through the use of the drug on this trial. Whereas, for people with RRMS who have less severe mobility problems, their walking would improve. As neither the RRMS or SPMS patients improved in the 25-foot test, the trials results were negative. Although, for people with SPMS, their upper-limb function did improve, which was recorded by the 9-hole peg test, but was not given enough importance in the reporting of the results of the trial. So, although the trial of the drug reported as negative, the drug had a positive impact for those patients with SPMS, as picked up by the upper-limb PROM and through their accounts.

shown in Figure 12, which was developed in 2001 by a team of physicians (Hobart, 2001). This was an important tool because it was one of the first to incorporate psychometric methods in its development.[15] PROMs (and other rating scales) map out people's responses as variables on a line where they can all be located. Psychometric methods evaluate the rating scales to determine their success at making the variable operational and locating people on this line. Psychometric methods are described as the theory of measurement and enable tools to become a measure by situating one person's response within a population of others. These methods combine 'the patient perspective with rigorous psychometric methods of data quality, scaling assumptions, acceptability, reliability and validity,' (Hobart, 2001, p. 962) to ensure that the final questionnaire would detect change in a person on the physical and psychological impact of MS.[16] In this tool, the patient answers 29 questions about how their MS affects their daily activities. Figure 14 on page 50 describes the standardised steps in the MSIS-29 PROM development process as endorsed by the Federal Drug Association (FDA). This shows the steps for using patient-derived data to generate PROM items.

In Figure 13 (Barrett et al., 2013, p. 810), the responses from the paper questionnaires have been turned into data in a spreadsheet. This acts like an inscription device where entities are translated into numbers, symbols and visualisations that are then considered 'facts' (Latour, 1987, p. 64). Star (1983, p. 270) describes this translation process as an essential part of scientific work where the presentation of cleaned-up results (from the messy labs, clinics and spreadsheets) are screened out through the production of graphs where facts are made. The graph displays the distribution of disability as concrete facts. This diagram is a typical visualisation of the responses to the PROM and acts as a demonstration of psychometric properties. These facts can then be transported, overlaid and calculated, becoming *immutable mobiles* (Latour and Woolgar, 1986) that can be acted upon. Immutable mobiles describes how representations of data such as this is made flat, which 'enables mastery' (Latour, 1990, p. 45) from the researchers showing this data. These immutable mobiles can go on to be transported without changing the inherent characteristics of those things as they are suspended in space and time through the diagram. They have agency as they are inscribed and circulate in the practices of healthcare, trial results, medical records

15 It is interesting to note that the incorporation of psychometric methods in measurement tools is relatively new in neurology, having only been introduced in the 1980s (Cano et al., 2011). None of the PROMs and health measures mentioned above have developed using the psychometric approach, including the most widespread physician-based measure, the EDSS (Kurtzke, 1983). The EDSS is now said to have limited measurement properties (Sharrack et al., 1999; Hobart, 2001) when analysed with psychometric methods as it is heavily weighted towards measuring mobility and does not account for other aspects of MS that impact people's lives. This has led to an inter-disciplinary dilemma within the health measurement field where measurement researchers argue for psychometric properties and standards to be created for all measures (Cano et al., 2011; Giovannoni, 2015). Yet, clinicians argue that the time and resources to create new tools is too high.

16 Data quality is concerned with the percentage of how many responses are missing and how much the target sample can be predicted from this. Scaling assumptions outlines a series of criteria for the set of items to legitimately form a single total score when values are given to them individually. Acceptability of the score is achieved when scores are well distributed across the scale. Reliability ensures that the scores are free from random error, and validity is whether the scale measures what it sets out to measure.

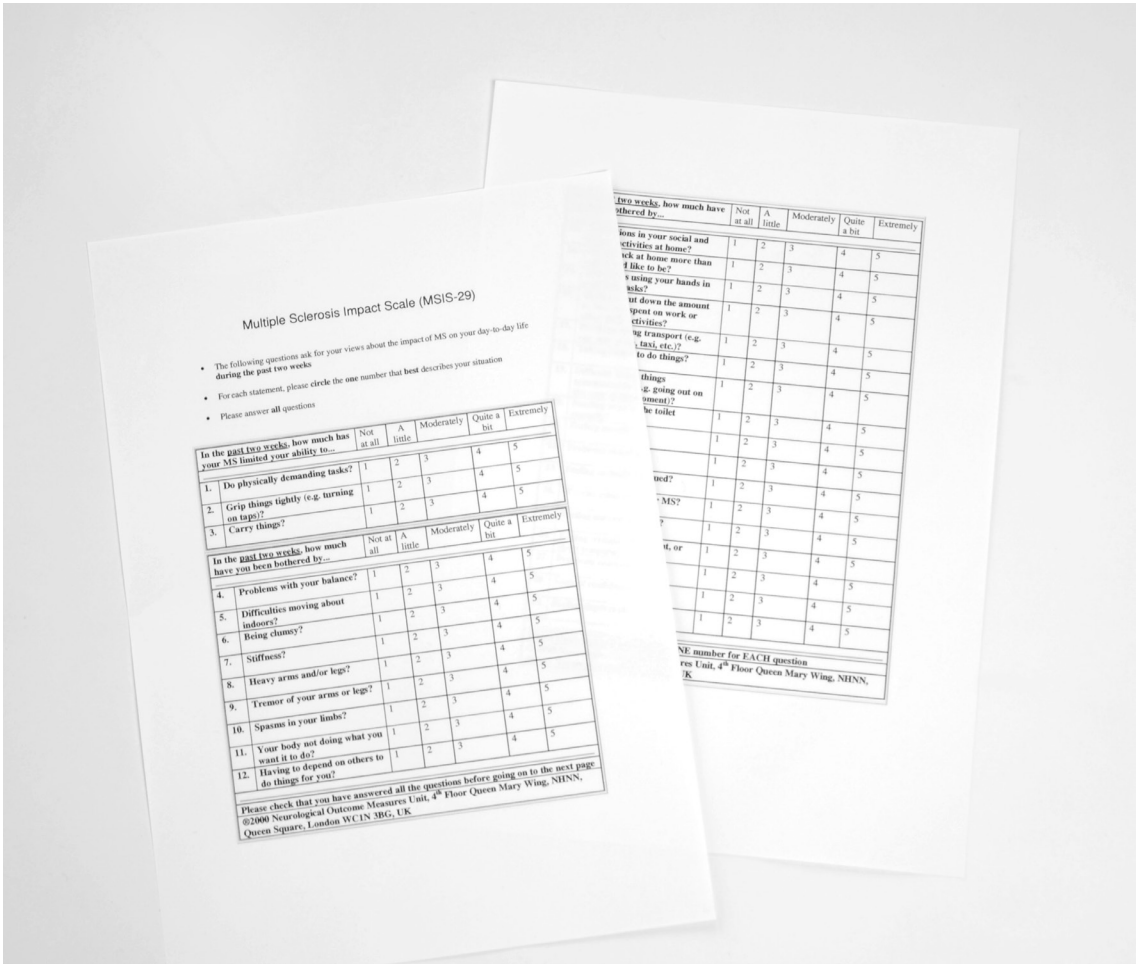


Figure 12 A photograph of the MSIS-29 paper based PROM.

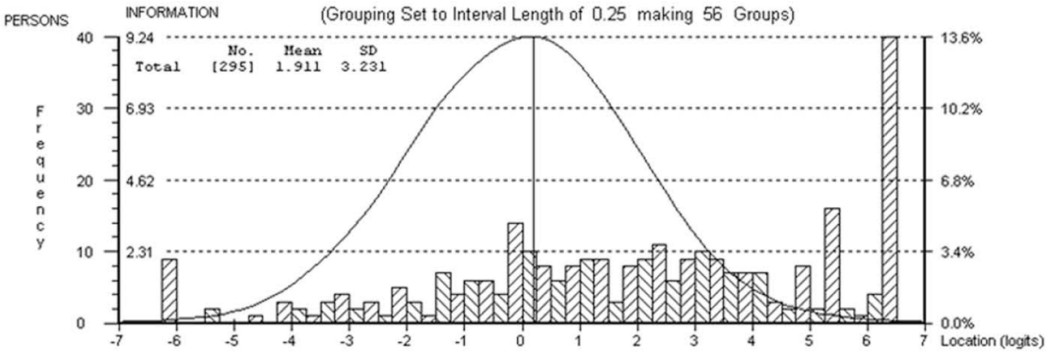


Figure 13 The diagram above shows the distribution of the manual ability of the people who have completed the PROM with people less disabled on the left and people more disabled on the right.

Step 1	Thirty people with MS were interviewed, expert opinion was consulted and a literature review was carried out to create 129 questionnaire items (questions) to start the development of the PROM.
Step 2	1530 people with MS were sent a questionnaire with the 129 questions on it.
Step 3	The 129 items were reviewed and reduced depending on statistical testing of data quality, scaling assumption, acceptability, reliability, targeting and validity. Data from 766 responses was analysed to determine which questions would make up the final questionnaire. The instrument now consists of 29 questions where people are asked about the impact of MS on their day-to-day life in the past two weeks. 22 questions relate to the physical impact of the disease and 11 items on the psychological aspects. Example questions in the tool asks, "In the past two weeks, how much has your MS limited your ability to..." · Do physically demanding tasks? · Grip things tightly (e.g. turning on taps)? · Carry things? Patients have the choice to select from a Likert Scale of 1 - 5 with 1 being "not at all" and 5 being "extremely."

Figure 14 Table describing of the three stages of PROM development for the MS-IS 29.

(Berg, 1996), diabetes technologies (Danholt, 2008) and screening procedures (Singleton, 1998) that circulate healthcare and design, far beyond the original patient and paper PROM. They are reproducible in that they can be printed and copied with little effort. Latour's printing press example (1990) demonstrates how ideas can be shared across the world without distortion and how their activity occurs through further process of publication.

This second model of experience is different and arguably incompatible with **Experience 1**. Where **Experience 1** takes patient-reported accounts of the subjective experience, **Experience 2** starts with this then produces numerical data creating immutable mobiles. Although, we can see how both versions typically and unproblematically operate in combination during clinical work of PROMs, they are not the same. As demonstrated through the ASCEND trial results (Giovannoni, 2015), the subjective experience of SPMS patients did not hang together (Mol, 2002, p. 55) with the PROM data of **Experience 2**. Following Anne Marie Mol, this is not a case of choosing one version of experience over another, but rather it concerns witnessing how different and divergent versions of experience, theories and practice hang together. This is raised by Callon and Rabarisoa (2004, p. 196) who point out in the French Muscular Dystrophy Association community, it is not about changing experiential knowledge to become accountable to the scientific and medical community, but about seeing the difference in the two forms of knowledge and giving them the same validity. The practical question for this thesis is how to work with different versions of experience symmetrically, without valuing one version as more valid or important than another.

Assumption 1: Failing to have Experiences

It becomes clear that there is more going on in PROMs than just measurement and representational activities. But, there are two practical assumptions about this approach to experience that should be explained. This technique of measuring presumes that people are not only physically capable of completing the questionnaire and recording information about their disease but are also reflexive, rationale actors. MS is a disease of the central nervous system and commonly affects peoples' cognitive functions; therefore these symptoms, practically speaking, could disturb the patient as a capable actor with the ability to read questions and write down answers. Firstly, this assumption is problematised in Jeanette Pols' work with people with mental illness where the consequences of understanding patient experience in this way says that if you do not have a voice or cannot complete a questionnaire, then you fail to have a patient experience (Pols, 2005; Carel, 2012). Literature from the ethnographic turn in the (STS) field of public understanding of science

(PUS) further examines how questionnaires are answered.[17] Alan Irwin and Mike Michael (2003) highlight that this assumption is reflected in the provenance of questionnaire methods in psychology where the person is viewed as a repository of knowledge that can be 'quizzed' (p. 24) over aspects of their knowledge or experience. The standardised questions (developed through psychometric validation) that are quizzing the patients create a generalised patient experience in which that respondents need to fit. Secondly, this raises questions of whether individual differences might be left out and what type of knowledge the patients might have. Pols distinguishes this difference between the knowledge of medical professionals and patient knowledge as it involves many different 'techniques, values and materials,' (Pols, 2005, p. 74). This is practical knowledge that has been developed through action – living with the disease. It is contextual and is based on the day-to-day experience of living with a chronic disease involving activities such as dressing, washing yourself and cutting the grass rather than through an evidence-based process. The reductionist PROM approach of science to experience potentially overlooks the fact that people possess relevant and useful knowledge that do not meet standards of scientific inquiry (Star, 1983, p. 206).

The reductionist generation of diagrams and immutable mobiles in the creation of experiences is also identified within design approaches to patient experience. Within EBCD approaches, diagrams are created and used to represent the patient journey through a healthcare service. Marked on these diagrams, shown in Figure 15, are people, objects, spaces, things, websites and locations referred to as touchpoints (Clatworthy, 2011) where the user and the service interact and it is claimed the service experience is created (Robert, 2013).[18] Through the process of visualising these interactions on temporary paper diagrams and making changes to points represented on the map, it is thought that different service experiences are created (Shostack, 1984). Arguably, this immutable mobile acts to reduce the complexity of both humans and the act of design into simple shapes and lines that can address a reduced form of 'patient'. As Latour describes in reference to Dagognet (1969, p. 213), the power of the visual vocabulary in chemistry, through the periodic table, enables the compounds to become actionable and manipulated. Through visualising the different human and non-human entities in the service, they can be assigned agency and be made

17 The field of public understanding of science, public engagement in science or public engagement of science and technology (these terms are used interchangeably) has been described as `a wide and ill-defined area' (Wynne, 1995). This change in the naming of the field demonstrates a shift from a deficit model of engagement (Irwin and Michael, 2003) where the notion of an ignorant public that needs to be informed has changed to a more upstream engagement model (Wilsdon et al., 2004) of engaging empowered citizens (Irwin, 2006, p. 301). Within the field, established and traditional formats and methods for engagements between scientist and the public were originally outlined in the Bodmer report (Royal Society, 1985) from consultations at both a national and local level, deliberative polling, focus groups, citizen juries, consensus conferences, dialogues with stakeholders etc. Contemporary practices of public engagement of science based within and supported by UK institutions take the form of awareness events, conferences, science cafes to arts and design projects.

18 This terminology has emerged in the language of service design (Evenson and Dubberly, 2009). The journey map has been developed from blueprinting where services are made an actual and visible object of design (Mager, 2008) which is similar to graphical representations of experience models, profiles, scenarios and opportunity maps to visually communicate service interactions (Blomberg et al., 2003). These are the moments where the service experience will arise and are specific points of interaction between a user and a product or brand.

Figure 15 A photograph of a patient journal map constructed in a EBCD project representing the stages in the health service that the patient can interact with.

workable. Star (1983) makes this point about science, but is applicable to design, describing how to conduct scientific research, things must be drawn, tasks must be made simple and goals must be made easy enough to achieve (p. 207).

The agency of this type of design is through both the visualisation and manipulation activity. Discussion topics could include how patients are approached by staff, the day-to-day working practices of the staff, information that is provided and procedures that take place. Literature about users from design and STS (Akrich, 1992; Suchman et al., 2002b; Danholt, 2005a), specifically Wilkie's definition of user assemblage (2010, p. 58), highlights the multiplicity of users that get both resourced and defined through the design process. Within the stages of the service design process, post-it notes are used as objects to determine current experiences and are also used to talk about future possibilities, identities and capabilities of existing, emergent and future users. Taking this further, Wilkie explores the performative potential that these temporary objects have when used in the prototyping activity (2010) and explores how each note could bring one potential future into being over another. The diagram acts as a distributing and collecting device (Berg, 1996) where the experience begins and ends. Although the diagram aims to simplify and make this a transparent process, involving people and eliciting patient experiences is complex and messy.

This raises questions as to what counts as experience. For designers, do they think that making changes to a simplified diagram, visualising a service counts as an experience? This is one of the criticisms of the EBCD approach (Bowen et al., 2013, p. 242). ANT puts forward the argument to re-consider what is thought of as facts. For example, **Experience 1** is typically viewed as a pre-existing property of humans that need only be correctly recorded. Or, **Experience 2**, which is produced and circulated through PROMs and documented in material objects, become representations of people's diseases (Berg and Bowker, 1997). When actually, all the recording apparatus, medical expertise, measurement techniques and so on recede into the background or get erased ('bracketed out', in Mol's language) to meet the factish demands of medical epistemology where it ultimately is presented as knowledge produced through scientifically rigorous methods. Arguably, however, what actually counts as experience is the upshot or effect of all these human/non-human relations.

In this thesis, I draw on ANT-inspired approaches, where experience is not a priori property of humans as cognitively endowed persons (**Experience 1**). Here, experience emerges out of the situated interplays between MS patients, medical technology, measurement tools, design practices and clinical expertise and draws attention to the relationships that all take part in patient experience. The following discussion is going to elaborate on and explain **Experience 3**.

Experience 3: Opening the Black Box

> **Experience 3: This third understanding emerges out of the situated interplays between people, measuring instruments, diagrams etc, which are socio-materially mediated. It argues that 'experience' is the result of these practices, devices etc. and cannot exist without them. It is performative in that it has agency, can cause other actants to act and produces subjects. Experience 3 is constituted in relation to various elements with there being no single central core. There is an indexicality of this experience where it is dependent of where it is embedded.**

In the case of MS, the MSIS-29 in the PROM produces a measure of the patient's HQoL, making it seem as though the HQoL is a fact that exists before the process of creating it. Following ANT, I would argue that the HQoL does not exist before or without the questionnaire, the spreadsheet and the process of calculating it. These recording devices can be described as *technologies of elicitation* (Lezaun and Soneryd, 2007) where the PROM acts an instrumental tool to elicit (and in doing so shape) patient experience, which raises questions about the conditions, procedures and instruments for producing knowledge. This patient experience data is co-produced (Pols, 2005, p. 211) in the liveness of the measurement activity which includes bodies, researchers, recording equipment, and many different entities coming together. If thought about as *pervasive technologies* (Lezaun and Soneryd, 2007) the conditions in which **Experience 2** is produced is available for analysis. This, then, raises questions around the efficacy of these methods to uncover and 'represent' an authentic patient experience, and if patient experience is produced at all through these techniques (Pols, 2005). In science for example, Boyle set out the conditions needed to create authentic knowledge through an experiment. But I ask the question, when there are different types of knowledge hanging together, what types of conditions create them?

Latour's notion of immutable mobile shows how the PROM makes experience a concrete entity that can be acted upon, for example, to participate in clinical practices. In this thesis, I claim, measurement tools also produce new versions of experience. There is currently a preoccupation in sociological and cultural literature about questions of method and the realities they are purposively reporting on where research techniques (or measurement practices) contribute to the shaping of new phenomena (Osborne and Rose, 1999; Mol, 2002; Law, 2004). For example, members of the public's opinions are elicited through opinion polls, and through this, the seemingly objective fact 'public opinion' was created (Osborne and Rose, 1999, p. 1). Similarly, Lezaun describes how knowledge

about people is generated from their opinions shared in focus groups, which then produce statements that help form particular marketplaces (2007).

The presumption that has been set out at the start of this thesis is, within healthcare, patient experiences need to be made reportable and accountable for commissioning and service provision reasons (e.g., to measure the financial effectiveness of service improvement activities), and it is the role of the researcher to research, measure and produce representational material about this.[19] Similarly, when designers are said to design and change patient experiences, they visualise it. But scholars interested in performativity would argue that, through the process of measurement and representation, patient experience is *performed*. In other words, specific versions of patient experience are an upshot of the measurement and representational devices, which is a key argument of this thesis. This claim requires a close consideration of how knowledge is produced and a sensitivity to the techniques, situations and objects that are involved in this process. Here, Andrew Pickering puts forward what he calls the *performative idiom* (1995, p. 13), where the empirical context is considered as having the ability to produce something new. This is a performative understanding of science and knowledge practices, where tools, such as PROMs, measure entities and phenomena while producing and verifying facts. It is important to note that the performative understanding of (patient) experience has a key implication for an important assumption in this area of research. Performativity provides an alternative way to understand how experience is produced: it is not predicated on the assumptions of a subjective individual with cognitive capabilities, which phenomenology and areas of nursing research have encouraged. Nor does it limit understandings of patient experience to the objective body of any person that a disease might inhabit (Mol and Law, 2001).

Performativity has important implications for how to think about patient experience as a topic of research and for how to understand how design operates and might be practiced. The notion of performativity has been increasingly used within the humanities and social sciences to problematise the representational idiom of science, economics and the arts where language is understood as that which reflects states of affairs. The notion of performativity is frequently traced back to John L. Austin's (1976) series of lectures from Harvard University in 1955. Here, Austin states that there are two types of speech acts: constative and performative utterances. Constatives are descriptive statements which can be either true or false. When, for example, someone says, 'I went to the hospital', they are reporting on a matter of fact, and this statement can be true or false. They either did or did not go to the hospital. However, as Austin describes, performative utterances bring a state of affairs into being and, thus, perform reality. The term performative derives from the word

19 I discuss the reflexive role of the design researcher in producing accounts of the research and new knowledge (Woolgar, 1988) in the methodology chapter.

'perform' relating to the noun 'action', indicating that language has agency and the capacity to create action. The example that Austin puts forward to describe this is uttering the words, 'I do', in a marriage ceremony. Here, the speech act is actively doing something in that moment (confirming the union of two people in matrimony). In other words, a performative speech act operates to bring new realities into being, rather than simply reporting on existing states of affair. Similarly, when we say, 'I promise to…' these words engage in the act of making a promise to another person that will (or should) affect the consequences of our actions.

According to Austin, for a statement to be performative, it needs to happen within 'appropriate circumstances', (1976, p. 6) or *felicity conditions*. These circumstances can include the words being uttered by an appropriate person (e.g., someone who is able to conduct marriage ceremonies), the act happening in a suitable context, the correct words being spoken and the interests of the utterer being considered. This can be further illustrated by way of diagnosis in clinical settings. Here, for example, if I were to sit across the table from someone in a hospital consultation room and tell them they had MS, the statement would not act as a diagnosis of the condition, as it would have no performative force for that purpose. I am not a trained neurologist, and the person does not identify me as such. Similarly, if a neurologist was to tell his pet dog that it had MS, then this statement would have no force. More accurately, it would not have an appropriate force because, for example, the dog might respond, but it would not be in relation to the semiotic valence of the statement, making the context inappropriate. Dogs do not develop MS, and it is in not the neurologist's interests to diagnose his dog. Following Austin's understanding of the performative utterance, it is the combination of the specific language used and the ability of the circumstances to set in motion a chain of events (further tests, scans, examinations etc.) that gives the speech act of diagnosis its performative force. The reliance on these circumstances suggests there is an indexicality of performativity in how statements can be considered reliant on the context in which they are embedded to make sense (Garfinkel, 1967). In other words, the meaning of the words 'You have MS' changes depending on the context in which they are spoken. Taking them out of this context not only changes the meaning of the words but also changes their agency. Felicity conditions is the precise point that current debates around performativity hang and I will come back to later.

The notion of performativity was first taken up and developed by feminist scholar Judith Butler, who has played a leading role in exploring the performative power of speech acts when applied to gender in feminist and queer theory. Following Austin and Jacques Derrida, Butler removes the focus from the utterer and puts more emphasis on what is being said in performative acts. Butler's (1990) approach to performativity shows there is a disconnect of linguistic agency from the human speaker. She argues that the power of the speech act is not entirely dependent on the person uttering the words, but it is the actual words they say. This puts forward an understanding of gender and sex formations not as

expressions of an inward nature but as performative acts. In other words, gender does not happen at birth, but it is a repeated sequence of acts that construct, and create, an identity. The implications of this for patient experience is that patient statements recorded and distributed through PROMs do not just report on events that a patient has experienced, they actually perform (deliver the action of creating) the patient experience. The statements 'speak' by way of being material-semiotic entities. This is the upshot of the translation process that begins with the conversion of patients' responses into data. Patients are performed through all kinds of linguistic activities (such as diagnosis, examinations and descriptions of symptoms) and, so by extension, patient experience. This goes further than the indexical nature of Austin's performative utterances, and for Butler, these statements, once produced, have the capacity to act beyond the original location. They create versions of patient experience which then are used to refer to the patient in other contexts (dependent on specific felicity conditions). This is where Butler, drawing on Derrida's (1988) reading of Austin, situates the effects of performativity. For people with MS, once versions of patient experience are measured and brought into being, they cause different effects such as affecting the disability benefits for that patient, limiting their access to treatments and affecting the results of a drug trial. The statements contribute to the performance of instruments of experience. These are consequences of the performative act and can have important impacts on people's lives. This is why performativity has been the focus for many humanities and social science scholars as semiotic and material processes can produce and transform reality. Butler locates it in the 'performative act' (1988, p. 521), meaning that performative agency is not in a pre-existing subject that exists before language, but is an effect of the process of citation. This suggests that patients, and experiences, do not pre-exist particular clinical and healthcare mobilisations, they are performed through and because of them. They are constructed in these encounters. This hints to an indexicality of experience which points to what else needs to be in place – the felicity conditions that Austin previously mentioned. Butler explains that this is how subjectivity is performative, as it is something that is done in an ongoing practical process. Gender, or for that matter being a patient with MS, is not a fixed and stable attribute of a person. There is not a pre-existing subject that people enact, or not, each day. Butler argues that people are always in a process of reiterating, producing and maintaining their subjectivity through their actions. Patient experience is something that is done and needs to be re-done every day in different situations. Another way of thinking about this would be as an achievement or *situated accomplishment* (Lynch, 2001, p. 140) – an ongoing, collective, and practical process. These accomplishments are generated on every occasion by different actors, and this process does not just involve language but also action and things. This is an extension of **Experience 3**, which opens up the analytic possibility of other non-humans acting.

Karen Barad provides another prominent approach to performativity, suggesting a more post-humanist understanding of the wider practices that enable patient experience

to be produced. This is focussed on the idea that non-humans can contribute to the performance of both human and non-human arrangements. Like Butler and Austin, she questions the representationalist assumption of science by disagreeing, arguing that entities do not have prior attributes and there is nothing out there waiting to be represented as knowledge (Barad, 2003). Along with Pickering (1995), Barad argues that the world is full of agency and that we, the observer or researcher, are part of this ongoing 'intra-action' (2003, p. 815). Barad describes how if things do not have prior attributes, then they become or are made in the moment when intra-action occurs. It is through this intra-activity, an iterative and reciprocal two-way process, that specific entities and phenomena come into being, and they are all part of this doing, or process of *becoming*. It is thought that through a process of becoming, both knowledge and a new existence is produced. This process of becoming involves different *things* described by Peter Danholt (2005b) drawing on Isabelle Stengers (2000, p. 148) as vectors of becoming which are brought together. Alfred N. Whitehead (1978, p. 23) describes '*How* an actual entity becomes constitutes *what* that actual entity *is*... It's "being" is constituted by its "becoming"'. Considering this, and work by Wilkie (2013) on design prototypes, enables me to view patient experience not as objects and subjects, but rather as a process (of *experiencing*) that undergoes continual change. The measurement tools, patient body, subjectivities and clinics co-become and are mutually defined in the measurement process. Key here is that this change is dependent on the felicity conditions that are contained within the moment of becoming. Danholt, who says this becoming is a located practice where the outcomes are always indexical, echoes this.

This understanding has profound implications for conceptualising patient experience, suggesting that it is not attributed to the physical body, like Butler argues, as a predefined property, but it is a 'doing' through performative actions and gestures. If the subjectivity of a patient is not pre-existing, nor determined by the body, then the cause of it is the effect of a practice making it happen – or as Butler describes, recitations of cultural norms which regulate it (1990). For patient experience, this then includes the material and physical PROMs, interviews, consultations and the human, material, object and nonhuman elements that surround the patient. Callon accounts for a combination of the performativity of language and action as happening within the performative utterances. He draws on the work of Deleuze and Guattari and the notion of assemblage which is neither linguistic nor outside of discourse to describe how heterogeneous agency and (non-human) action is achieved (1986, p. 4). He describes that it is within the heterogeneous socio-technical assemblage of actor-networks that material-discursive entities exist.

For Butler, gender can be removed from the object, the physical body, and performed, and similarly, the patient experience can be performed away from the body of the patient through things such as data visualisations, diagrams and service maps which all do this work. Although this also means, following Barad's rethinking of entities, not having a priori attributes calls into question the 'givenness' of the categories of human and

non-human. If nothing has qualities before it is interacted with (and if the subject/object divide is removed, or the man/machine distinction removed [Suchman 2007]), then there is no distinction between human and nonhuman and everything has the ability to act, then everything has agency, raising the question of who and what has agency to perform.

Performativity has become a widespread conceptual resource across many substantive areas of gender studies (Butler, 1990), economic sociology (MacKenzie and Millo, 2003; Callon, 2006), social and cultural research, and design (Danholt, 2005b; Ehn, 2008; Yaneva, 2009; Wilkie et al., 2015); however, it is not without its critics. In the field of economic sociology, Uskali Mäki (2013) establishes some interesting arguments as to why the notion of performativity has become confused when developed beyond its Austin's original purposes. Mäki describes how modern finance theory performs the financial market (MacKenzie, 2004). He also describes how MacKenzie, in his three definitions of performativity, 'generic', 'effective' and 'Barnesian', (Mackenzie, 2006, p. 17; MacKenzie, 2008, pp. 55–56) misinterprets the 'direct constitution' that is required for something to be performative. Mäki argues that Mackenzie's use of the concept misinterprets this for causal influence, i.e., there is no constitutive, or direct, relationship between the economic theoretical model and the empirical practices or the effects that MacKenzie claims are performative. In other words, the effects on the economy are not actually directly caused by the performative claim, but by other things. In light of this, Mäki calls for a returned to Austin's original understanding of the term and for the emphasis to be placed back on the felicity conditions. Before I going further, I will outline three other key critiques of performativity that are relevant to this thesis and my understanding of the term.

Assumption 1: Backstage Performances

Erving Goffman's dramaturgical model of sociality (1990) views human interactions as theatrical performances. This model uses the analogy of the stage and its associated actors, where people perform for an audience on a stage with curtains frontstage, and there is also the existence of a backstage for preparation to conceptualise performativity. This analogy can be problematic as it can lend itself to misunderstandings of the term where humans have the ability to choose the staging of the interaction in their daily lives, the objects involved in it and the audience they would perform to (Mol, 2002). But, this would presuppose a cognitive decision, referring back to **Experience 1**, where patients would be cognitively aware of their inner subjectivity and could choose what they wanted to perform, insinuating that there is a 'doer' behind the deed (Salih, 2007). This is quite different from other scholars' understanding of performativity who argue that performativity is an action brought about through the happening of a situation. To move away from these misconceptions, in *The Body Multiple*, Mol suggested renaming performativity as enactment to move away from theatrical connotations. Since then, the term enactment has been taken up in a number of health studies (Berg and Bowker, 1997; Law and Singleton, 2003;

Lin, 2013), but arguably, this renaming is not really doing much more because scholars (Mol, 1998, 1999; Law and Urry, 2004) tend to use the two terms interchangeably, but more importantly, they are not engaging in the critical debate around the theoretical and empirical use of the notion of performativity (Mäki, 2013).

Assumption 2: Performativity of Language

In Austin's original description of performativity, agency is clearly displaced from the utterer to language. Callon's (2006) work on performativity of financial markets draws attention to the socio-technical networks of agency, providing a basis to criticise the emphasis on discourse. From an ANT-informed perspective, as well as discourse analysis, language and semiotic entities can thus be seen to have agency. A good example of this can be found in Monica Greco's (2012) work around medically unexplained symptoms. Here, medical research literature has performative effects when naming and categorising the range of symptoms that people are experiencing that cannot be explained. This work acknowledges the performative power of words through analysing the effects of the rejection of psychological dimensions of these unexplained symptoms by classifications by the medical community. Further, Mark Learmonths (2005) analyses the performative and non-performative effects of language practices used within and around administration and management in the NHS, and Lars Nordgren (2008) traces the performativity of service management discourse in the linguistic usage of the customer concept in healthcare as going from a passive recipient of care to a co-producer of care. Evident in all these examples is that the performative dimension stays with language. They draw on Butler (1993) who, although going on to talk about the body, is unable to move away from the construction of language as the performative force. Mol (2002) also highlights that Butler's performative construction of female identities fails to consider the materiality of medical instruments and female organs.

Assumption 3: Performativity of Non-action

Up until this point, I have developed an understanding of performativity where some form of action or agency is happening that can involve some combination of humans and non-humans. This view depends on there being a resulting effect of the performative act. This would then mean that if there is no end result, then something is not performative. However, I would argue there is the possibility that sometimes interventions produce effects and sometimes they do not. Note that this is different from saying that something has failed to be performative.[20] Nevertheless, what does this mean empirically if some

20 Christian Licoppe (2010) describes how every social performance is open to failings, as well as creative invention. Moreover, performative action is continually being repeated, however, following Butler, there is no guarantee of the same subject being produced. Licoppe provides an interesting example of video communication technology being used in a French courtroom where the video fails to deliver the performative instruction from the judge in one room to a security guard in another.

things fail to produce effects? Hennion and Gomart illustrate this through their work with drug users and music amateurs where their 'active passion' is the effect of an experience with something (1999, p. 220).[21] Their description of a sociology of attachments describes the active passion and performative relations that humans can make to objects and situations. They apply action beyond ANT concerns around who is acting in the network, to questioning the limitations of action suggesting that within events there can be active and passive modalities (p. 222). For example, with drug users, even though sometimes there is no physical effect of their addiction visible on their body, the addiction is still performative and does not make it any less real. Hennion and Gomart justify this move away from ANT in critically saying that ANT does not allow access to *events* that are not actions. Their argument is that ANT is preoccupied by asking 'Who' acts within a network, which implies both human action to objects and a perspective on the network itself.[22] Instead, they propose that we start to consider 'what happens?'. This also aligns itself with Butler's description of performativity not being a single act, but a series of repetitions. If everything is constantly performing all the time, then what enables some actions to create effects and consequences and others not?

Performativity has been taken up as a way to inform design practice in regards to how designers perform future users in the things they make (Niedderer, 2007) as well as inform theoretical accounts of design practice (Danholt, 2005b; Wilkie and Michael, 2009). Work on the performativity of prototypes (Suchman et al., 2002b; Danholt, 2005b; Wilkie et al., 2015) describes how prototypes can be performed in how they shift between the present and the future. Danholt (2005) makes the case for considering the fruitfulness of thinking in terms of performativity in design in his study where he develops a diet diary for users with diabetes. Moreover, he considers how including users and artefacts in a design process affect each other. Described as socio-material prototypes, the interaction of socio-material forms are concrete and present as well as imaginary and futuristic (Danholt, 2005a, p. 5). This is a materiality of performativity where the material contributes. Through the prototyping process, the interaction of objects and bodies, subjectivities and bodies are also produced. Designers play a part in this production through the objects they introduce to this situation.

This is where I anticipate there being space for this thesis to contribute, as it works with a performative understanding of experience that is currently used in both medicine and design. For example, a popular tool used in design are *experience prototypes*. Developed by IDEO, designers use proxy objects (camera, diaries) to attempt to access 'first hand appreciations' of (p. 424) particular situations, such as living with a pacemaker, travelling on a train or living with a physical disability (Buchenau and Suri, 2000). This approach

21 This understanding of experience is similar to John Dewey who describes the experience of art as a mix of doing and undergoing where the subject does not bring it about, rather it is something that overwhelms us. See (Dewey, 1934).

22 This echoes some of the criticisms around ANT and how agency is described as 'managerial' (Star and Griesemer, 1989; Fujimura, 1992) as well as Haraway's criticism of a world where everything is performative, where there is no innocence. See Haraway (1991).

aims to enable designers, clients and users to experience something themselves through staging **Experience 1** for others around specific situations. This is a different understanding of prototypes from that of experience prototypes where designers attempt to stage a performative effect for others but are unaware of the potential multiplicity of performative effects. I would argue that such tools, experience prototypes, also operate to engender commercial practices around the design of experiences that are similar to a first-generation understanding of the experience economy.

Experience 4: Experience and the Event

> **Experience 4: Distributed and de-centred experience where agency is dispersed. It is not pre-existing and can have no visible effects. It is dependent on felicity conditions. This understanding of experience is influenced by the notion of event to consider the situated action of this model of experience.**

This brings me to the final understanding of experience that I have identified in the literature, **Experience 4**. Mariam Fraser's notion of event (2009) can contribute to the critique of performativity to understand how performativity reduces or centres agency to particular acting entities – neurologists, drug users, patients and measurement tools. Drawing on Deleuze's version of event, Fraser describes it as more than just something that happens. It is described as the coming together of entities that are social and material, human and non-human. The 'giving up action for events' (Gomart and Hennion, 1999, p.2) seeks to describe the relations between things, bodies and happening, and the independent reality of these events in themselves. I will use an example of an event in MS to illustrate and examine this critique of action from the literature. The recent controversial case of the unproven Chronic Cerebrospinal Venous Insufficiency (CCSVI) therapy as a cure for MS was escalated through the use of YouTube (Mazanderani et al., 2013).[23] The scientific and medical community disassociated with this therapy because it was scientifically unproven (Gafson and Giovannoni, 2014), whereas the patient community endorsed it because it claimed to provide miraculous improvements in walking ability and cure people (Benjaminy et al., 2018).

Between 2011 and 2013, a range of videos started to appear on the internet of people with MS sharing their experience of the CCSVI therapy before and after they had the procedure. In these videos (Figure 16 and Figure 17), the patients carried out medical

23 CCSVI is a reported abnormality in blood drainage from the brain and spinal cord. In 2009, Dr. Paolo Zamboni from the University of Ferrara in Italy published a hypothesis that this may contribute to nervous system damage in MS. This hypothesis was both socio-politically and scientifically controversial and went viral via social media informing many people with MS about the therapy. Since then, Dr. Zamboni's results have not been validated, yet many people with MS have undergone the therapy. This situation is particularly interesting due to the role that social media played in the development of the controversy around the treatment for MS. See Gafson and Giovannoni (2014).

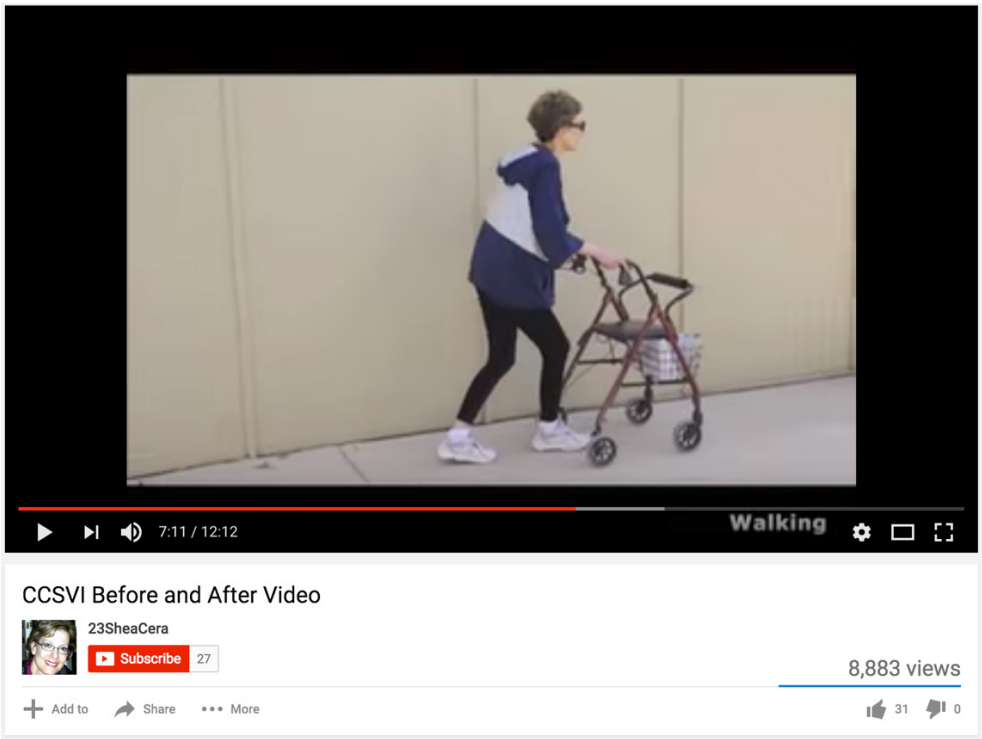


Figure 16 Image still of a YouTube video where a person with MS is filming herself walk as far as she can after receiving the CCSVI treatment (Source: 23SheaCera (2011). CCSVI Before and After Video. [video] Available at: https://www.youtube.com/watch?v=NoAdoNSvUbI [Accessed 19 March 2015]).

Figure 17 Image still of YouTube video where a person with MS films herself walking with a cane before receiving the CCSVI treatment, and then without the cane after the treatment (Source: kumquat509 (2010). Barbara Before and After CCSVI Video. [video] Available at: https://www.youtube.com/watch?v=Hn6p9R6fQaY [Accessed 10 March 2016]).

outcome measures to demonstrate their improved physical ability and fitness, particularly people walking further than a previous video after the treatment. These videos consisting of personal stories (**Experience 1**) and the completion of medical outcome measures (**Experience 2**) created action and enough evidence for other patients to go out and get the dangerous therapy. There was a widespread increase in the number of patients going to get the treatment who then reported back in the same format. This example shows new and novel ways that experience circulates outside of the expert setting.

Using Fraser's notion of event, it is much more difficult to identify where the agency is in this situation, but it does give importance to consider the materials that are actively involved in the production of experience. Is it the person filming themselves, the technical capacity of the camera, the home environment, the use of examples of things they can and cannot do or the aesthetics of the video, or is it a combination of all the above coming together? It is these specific felicity conditions that are part of the process of becoming, creating these versions of patient experiences. Gomart and Hennion (1999, p. 416) describe these as 'mediators' that 'are not passive...but active producers'. Also, all of the entities existed before they came together, but changed in this process. The medical information existed in the clinic, in journals, at scientific conferences and the patients interacted with this knowledge through healthcare professionals. Within these videos, patients were adopting, adapting and appropriating the practices of medicine to demonstrate differences in their disease. Viewers of these videos were interacting with medical knowledge along with experiential knowledge through the videos, and this became very problematic for the medical community as it created something else, while also changing that which was involved. Everything changes in this coming together – the drug user (Gomart and Hennion, 1999), the researcher (Michael, 2011) or the user with diabetes (Wilkie, 2013). So regardless of the scientific community rejecting the therapy, scientific knowledge and the medical community were part of the becoming of these experiences. Some of these are analytically available and others exist where access is not possible. Stengers describes how events occur outside the control of any single actor and the effects of an event remain unknown and unknowable (2000, p. 66).

The concept of the event highlights a process where patients, experiences, practices, tools and researchers co-become, which is currently being discussed in design literature (Wilkie and Michael, 2009; Wilkie et al., 2014; Jönsson, 2014). The focus of this discussion is on how design can work with the potential of events while acknowledging the performativity of method. In other words, moving away from the idea that experiences can be designed or scripted as, ultimately, entities may do something quite different from what the designers intended. This is an opportunity to use the research event to ask more inventive questions about what could become in moments of interaction between patient, bodies, clinics and measurement tools (Wilkie et al., 2014). In relation to my thesis, what potential combinations of things (humans and non-humans) can be brought together in

designing research events to consider forms of patient experience? Answering this will then push to imagine, and create, new forms of patient experience. Also, what changes through these events and how? What conditions need and should be in place to direct this? What are productive felicity conditions?

This focus on event over actions when thinking about patient experience allows me to consider the limited access to events that are not actions and the limited ways of relating to patient experience when it is not being measured. In developing a working definition of performativity to take forward through this thesis, I understand it as a development from the performativity literature which opens up the view that entities can do things, which is precisely the point that ANT makes, but along with becoming and event, it says that things can change in this process of action. By taking up my previously developed definition of performativity around the notion of event, I can think about the design process, and moments of design, as where multiple and diverse elements come together and, in coming together, change one another (Wilkie, 2013, p. 4).

Conclusion

In this first chapter, I have examined literature around four different versions of patient experience. **Experience 1** describes the phenomenological approaches dominant within healthcare and design methods, such as EBCD. ANT points out how this understanding prioritises the subjective mind within humans, rendering them capable of having experiences. Drawing further on STS, **Experience 2** is the immutable mobiles version generated through quantitative tools and design inscriptions circulated as data and visualisations in health measurement activities and EBCD processes. After this, I explore how **Experience 3** is a performative result of the situated interplays of patients, objects and measurement practices and yet is limited by assumptions related to performativity around backstage analogies, terminology and limitations of recognising performativity as capable of only producing visible effects. Finally, **Experience 4** calls for a distributed experience around the notion of event. By pulling out assumptions within these versions and considering how they either successfully or unsuccessfully hang together, patient experience as a knowable, concrete entity starts to unravel.

The table of experience, shown in Figure 18, has now been populated with few exceptions with the different versions of experience identified throughout this chapter. As can be seen, there are two blank boxes marked with question marks at the bottom right of the table. These identify, at this stage in the thesis, unknowns. It is here that I am focussing my research and hope to contribute. I very much see this table as marking out the practo-theoretical boundaries of this thesis and will return to address these empty boxes at the end of Chapter 5.

Moving on to the methodology chapter, STS provides sensibilities on how to look at the empirical situations where accounts of patient experience are co-produced and highlight

the attention that must be paid to the particular conditions in which such expressive arrangements take place. I will also take forward an understanding of patient experience as a situated accomplishment that is indexical to its site of production and to its locale of circulation. In light of the strengths, weaknesses and challenges set out in the performativity literature, I argue that performativity is an important conceptual tool for understanding how patient experience is constructed and mediated in practice, and that this performativity is situated, indexical and dependent upon particular felicity conditions.

	Description	Assumptions	Design approach
Experience 1	This first understanding of experience is of a patient's inner, subjective experience of events that has happened to them. This understanding is heavily influenced by phenomenology and is dominant in healthcare practices that treat patients as subjective beings.	The limitation of perception where individual people view the world differently depending on their embodied perspective and ontological view. This also presumes that humans know their own minds and access their thoughts, i.e. their memories. STS would argue that this point of view prioritises humans as perceiving subjects above all others.	A first generation of experience design understands customers as being passive recipients of experiences that designers can create. A second-generation understanding likens experience design with co-creation and participatory design tradition where users are involved to talk for themselves and contribute to the change process. This understanding has underlying motivations of democratic principles of work management dynamics.
Experience 2	This version takes patient experience as a measured and objective phenomenon such as a number or a measure produced through data as generated from and reported through patients' subjective accounts. This version can travel and have agency in making subjects. This is not to be confused with the phenomenological perspective of experience, which is the 'inner experience' of a person, this notion is a generalised data version.	Presumes people are reflexive, rationale actors. If you fail to produce data, you do not have an experience. People are a repository of knowledge that need to be quizzed. Raises questions about the different forms of knowledge left out by methods to capture or represent this information.	Typical design inscription (immutable mobiles) that visually reduces knowledge production to simple and interrelated shapes. Action is ascribed to these shapes that are at the center of design activities.
Experience 3	This third understanding emerges out of the situated interplays between people, measuring instruments, etc. which are socio-materially mediated. It argues that 'experience' is the result of these practices and so cannot exist without them and has agency that can cause other actants to act and produce subjects. It is constituted in relation to various elements, and there is no single central core. There is an indexicality of this experience where it is dependent on where it is embedded.	This version rejects the object/subject divide, but as a performative understanding, it has been used to focus on language, presupposes a backstage where there is a consciousness and is limited to recognising performativity as producing visible effects.	An understanding of the design process as entirely performative where both subjectivities and bodies are performed. Socio-material assemblies of patients, measurement tools, health professionals, spreadsheets, etc. are performed that achieve different experiences. Can be simulated through experience prototypes and design tools.
Experience 4	This is a distributed experience that has distributed agency. It is not pre-existing and can have no visible effects. It is dependent on felicity conditions. This understanding of experience is influenced by the notion of event to consider the situated action of this model of experience.	?	?

Figure 18 Table of experience (unfinished)

Chapter 3: A Methodology for Studying Patient Experience

In this chapter, I describe my approach to studying a performative understanding of patient experience through design-led research. The chapter will start with the methodological rationale I have chosen to use in this thesis, describing a combination of conceptual underpinnings from sociology and design-led methods. I then provide a detailed description and explanation of my research method choice. Finally, I discuss the methodological issues and challenges I anticipate encountering when conducting a study of patient experience through design-led research.

Methodological Rationale

The methodological rationale of this thesis builds on the assumptions within approaches to patient experience discussed in the literature review from the fields of social science, medicine and design. These assumptions raise methodological challenges such as how to develop knowledge about patient experience that is not influenced by the method of knowledge generation and how different understandings of experience that are seemingly incompatible (e.g., quantitative and qualitative, ANT and subjectivity) can and are, in practice, made workable and hang together. Finally, it challenges what the implications of a performative understanding of patient experience are, taking into consideration the weaknesses that have been pointed out by critics of performativity.

The methodological rationale for this thesis is inspired by ANT approaches and the performativity literature which considers knowledge to not be pre-existing, fixed or stable. Rather, according to the literature, knowledge is produced through practices and interactions of different actors. For example, in *Enacting the Social*, John Law and John Urry argue that social inquiry and its methods are not only means of uncovering but also means of enacting because they can make social realities and social worlds. As already outlined in the literature review, the performativity of method views them as constitutive, meaning they do not only describe worlds but they also participate in, reflect upon and enact these worlds. Law and Urry ask the question to researchers and, in my case, to designers, 'Which realities? Which do we want to help to make more real, and which less real? How do we want to interfere (because interfere we will, one way or another)?' (2004, p. 11). Here, I take 'interfering' as intervening through design, contributing to making new worlds by adding new relationships, elements and capabilities. Therefore, I too am enacting a reality and version of patient experience through attempting to study it. Danholt (2008, p. 74) argues that 'When not subscribing to a sharp distinction between description and intervention, the repertoire of what constitutes intervention and thus potential contributions is considerably broadened'. So, in relation to this thesis, how can design construct 'good', better or different patient experiences? Within this, it is interesting to think about what the potential connections that could be made between different human and non-human actors through my research are, what might be brought into being, or more importantly, 'what should be brought into being', (Law and Urry, 2004, p. 6). This decision, or ontological politics (Mol,

1999, 2002; Law and Urry, 2004), describes how, or through which methods, we enact ethical worlds (and what kinds of ethics), shape new realities or design new tools for understanding and describes how these decisions are made and dealt with through design. Marc Berg (1998) argues that design is ontological politics and in doing so charges design with the responsibility of enabling certain outcomes whilst downplaying others. Law and Urry recognise the challenge of this methodological rationale (2004, p. 5); additionally, Haraway articulates there is no neutral position to research and describe the patient experience in a world where everything is performative (1988, 1991, 1994). So, my challenge is to think about how design research can move forward in this precarious position.

To start, I suggest that, by following Callon's notion of generalised symmetry, I can trace the networks that claim to make an **Experience**. Callon states that we must not constantly separate humans from non-humans when making these new entities and understandings of patient experience. This has been Callon's (2004) criticism of participatory design processes which solely consider the participation of humans actors and the resources available to them. Hence, when developing and researching alternative forms of patient experience, or designing new methods, it is not just a question of satisfying the needs of human beings involved in the process (people with MS, clinicians, MS researchers). Rather, it is also about enabling the non-human agencies in enacting future possibilities. This argument, along with Pols' (2005, p. 207) work describing how studying the patient perspective through talk only silences those without those capabilities, establishes why I am not directly asking people to report on their experiences. They would only produce **Experience 1** and support these human-centric assumptions.

In the previous chapter, I argued that experience is indexical to the site of its production and is dependent on felicity conditions. Therefore, in this research, I am aware of how the felicity conditions contribute to making different patient experiences and also take seriously the empirical settings (including things in them) that contribute to current versions of experience. In this research, I focus on the outpatient clinic, scientific conference and measurement activities that have been the subject of previous studies which observe the clinical practice (Singleton, 1998; Mol, 2002) and the scientific conference as a location where scientific resources are mobilised (Irwin and Michael, 2003). In her study on the patient perspective of people in mental healthcare, Pols (2005) describes that observations of 'situations' with specific characteristics will allow humans (and non-humans) to enact appreciations. As I go on to describe later in this chapter, for the practice-based element of this research, I develop three pilot studies to scope out these situations. A more in-depth rationale for the pilot study approach is described later in this chapter, with the next empirical chapter providing a full description of each study and an empirical account of what happened. Through practice-based design interventions in these spaces, I attempt to enact new patient experiences and test their 'success' or efficacy and, like ANT, open the black boxes (Callon, 1986; Latour, 1987) of experience to

shed light on the complex relationships that exist amongst all actants, from MS patients, clinical practices, knowledge and non-medical objects to measurement technologies. In doing this, I use a similar descriptive framework when faced with either a human, questionnaire, trundle wheel or tuning fork. This helps me see how actor communities rally, network and position themselves to become knowable, hang together and also fail (Callon, 1986; Latour, 1987). This proposes the empirical task of following and tracing the actors and complex assemblages of practices, materials and discourses in and through which patient experiences are made. So, similarly to Latour (1988, p. 255), I study the practices and processes of making patient experience, paying attention to the places where patient experience is produced, circulated, made stable and inscribed in the practices of healthcare. Mol and Law (2004) demonstrate it is the routine and in-situ enactment of these bodies, diseases and medical practices where different versions of patient experience are enacted alongside each other. By following the procedural process of PROM development (the measurement tool used to measure patient experiences of their MS), I follow the process of knowledge production. This highlights opportunities for exploration and also identifies assumptions within these practices. This includes, for example, the clinic site as a specific location where **Experience 1** is generated through consultations and measurement procedures, the scientific conference where **Experience 2** is circulated through poster presentations with the patient body absent, and **Experience 3**, which is generated through design processes. This research explores the potential for **Experience 4** to be brought into being through considering the notion of a research event.

This calls for a methodological engagement with the open-endedness of the social world where the object of study is multiple, and any intervention is performative. In *Inventive Methods* (2012), Celia Lury and Nina Wakeford build on Law and Urry's (2004) understanding of the performativity of method to propose an inventory of research methods that enable the happening of the social, rather than just capturing or recording the here and now. Lury and Wakeford give examples of research tools such as tape recorders, patterns and design probes that actually come closer to being devices or instruments that go onto expand the present as 'on going maximisation of the agencies involved in social life' (2012, p. 5). This description enables the happening of the social through these research tools, acknowledges a socio-material perspective and gives attention to the properties of the medium, which is a core interest of design practice. Designers are already aware that materials have different capacities within the situations they are deployed. For example, using a focus group, a post-it note, mapping tools or prototypes in the situation makes a huge difference in what is achieved. The articulation of inventive methods encourages working with the potential agencies that design can provoke where designed interventions can prompt emergent enactments of potential situations while highlighting problematic existing practices. Yet, *Inventive Methods* further articulates the implications of using design within this methodological approach. For example, the inventiveness of the design can

never be known in advance of its deployment within a situation. Although the design can have an intended aim, I do not know what the social world will do until the research event, and thereby the heterogeneous network of actors, goes live, bringing together participants, knowledge, resources, recording devices, spaces and speculative forms of design.[1] In relation to this, what emerges from the design is completely dependent and reliant on its relation to the situation in which it is used. This involves the agency and performativity of both human and non-human actors. This is a broader definition of method than used in more traditional social science. However, for design practice, I am engaged in working with the unpredictability of method inventiveness and in designing interactions that take the research context and specific problems into consideration. Moreover, I engage others in this process. Here, I think it comes down to a continuum of how things play out in practice with what is planned, what can be hoped for, what is brought forward in these moments and the capacity of what emerges in the use of design to address the problem.

Research Methods

This next section will give an account of the research methods I use to involve and engage people in this design research. I start with a brief background to the setting of the thesis, describing the current situation in design research as practiced in healthcare. I then describe the two main methods, the pilot studies and a research study involving three research events, followed by how these methods draw on engagement and involvement techniques currently being used in the health service, design and social science. In doing this, I highlight some issues, critiques and challenges of involving people in design research within healthcare context.

The practice-based element of this PhD thesis started in October 2012 and was a continuation of the work I was conducting as a visiting research assistant within the Barts MS research team at QMUL. Throughout the thesis I have held a research role at QMUL. As such, I have access to resources such as hospital and university spaces, conferences and lab meetings, as well as medical and scientific expertise that are relevant to the PhD research. It is important to acknowledge that this research is also positioned in the field of design research, along with engaging with the very specific field of MS. There are different definitions and understandings of design research which are generally described as research for design, research into design and research through design (Frayling, 1993), where the use of design within research is represented within these three different approaches. For this practice-based PhD, I understand design-led research to be when design practice has informed subsequent research, reflection and analysis, and where knowledge production involves the design and development of designed interactions. In other words, I practice

1 Michael (2014) provides an interesting account of a research incident with a cat and a tape recorder which demonstrates how non-human agency can intervene in a research event.

design through deploying interventions and use these events, and the interactions of different actors within them, as performative and empirical knowledge generating moments to explore new knowledge about patient experience (Sevaldson, 2010; Löwgren and Reimer, 2013). In this thesis, I am using design as a method to research my object of study, which is the different, future possible versions of patient experience (Jonas, 2007). So, I would describe this work as research through design where the 'process of iteratively designing artefacts as a creative way of investigating what a potential future might be' (Zimmerman et al., 2010, p. 312). This is a design epistemology where the designerly way of knowing (Cross, 1982, p. 6) is valued as an important part of the research process and is separate to the practice of design, which is an approach to knowledge creation (Wilkie, 2013). In other words, thinking about design and doing design can be separated. This is why this thesis is practice-based. Doing design involves the practical engagement with the messy practices of measuring, visualising, acting on and designing patient experiences which goes on to inform further thinking.

It is also important to keep in mind that the design practice presented in this thesis is not intended to solve perceived problems in the patient experience, nor is it to develop potential products or new services.[2] The intention of each design intervention is to redesign the relations that are enacted in the specific sites to change patient, clinician and medical interactions, as well as roles within the sites, to generate new knowledge by provoking the existing system structures. Therefore, the designs presented in this thesis should not be judged as standalone design outcomes or solutions, but as reference points in a research process of exploring new knowledge about how patient experience can be generated, altered and affected by introducing design. As such, the research in this thesis did not begin with a research approach or perspective. Instead, it has been guided and informed by my current and previous design practice.

Similarly, this methodology was not in place prior to the start of the PhD. Rather, it has developed as I engaged further with the literature and the practical projects. Both the establishment of the literature review and the results of the pilot projects contributed to the methodology and suggest further directions for the practice-based research. Figure 19 shows a reflective image of how the pilot studies feed into the design of the research study.

Pilot Studies: Engaging with patients, healthcare professionals and MS researchers

The three pilot studies are designed to further explore the assumptions within patient experience that are identified in the literature review. These are around different versions of experience hanging together, non-human agency and the performativity of design. The aim of the pilot studies is to empirically explore the conditions, procedures and instruments

2 I would argue that this PhD started from my observation of designers attempting to design for the perceived problem of `patient experience' in healthcare through approaches such as EBCD.

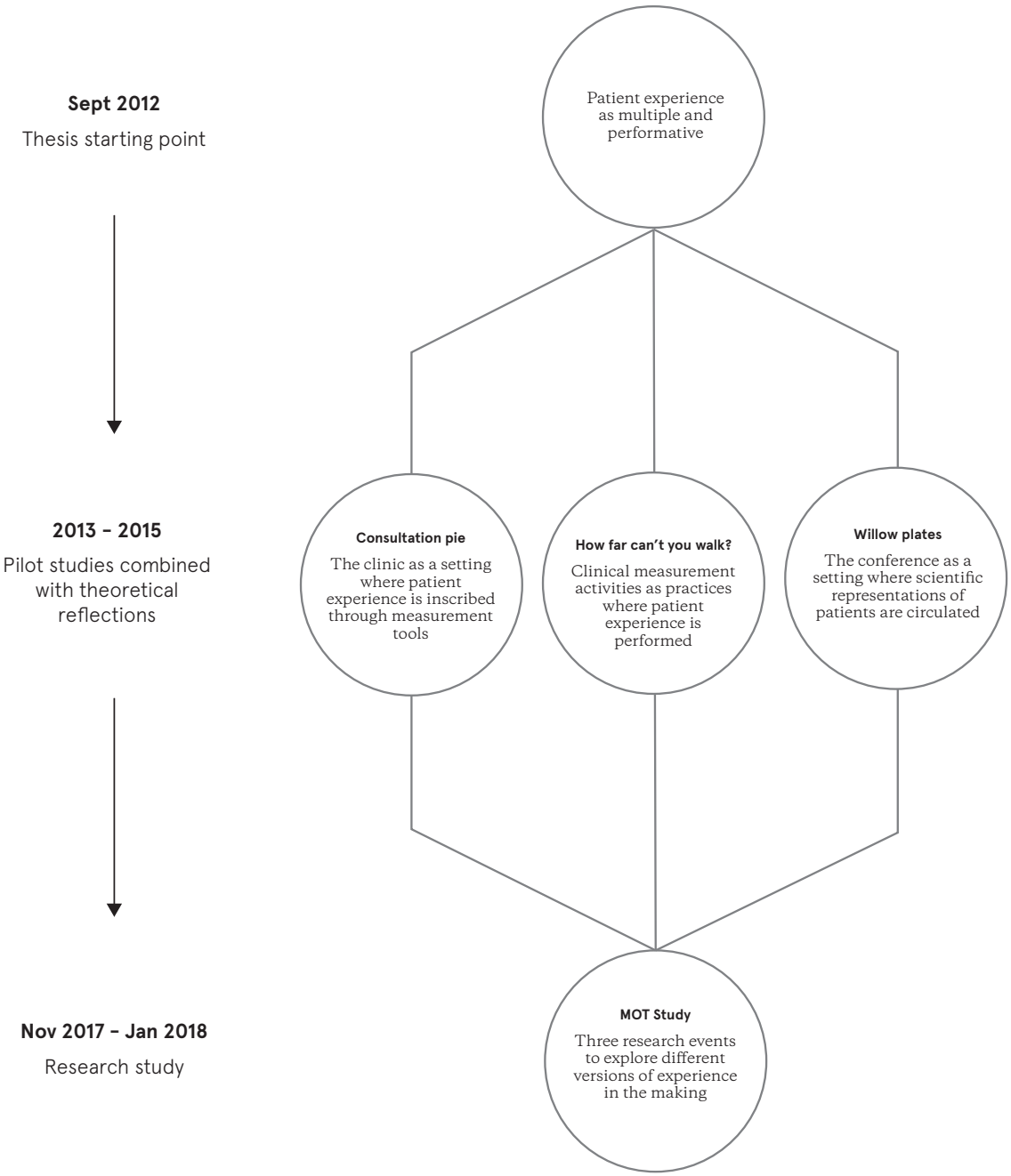


Figure 19 How the pilot studies informed the study design.

that produce knowledge about the different versions of **patient experience.** The pilot studies are designed from my previous experience of the clinic and scientific conferences as I am already familiar with the conditions of these sites (different groups of people, my role within these spaces, the technical apparatus, environment, procedures etc.). I explore the performative effects of deploying specific activities and objects to see what happens in these sites as the studies are designed to engage with the social world rather than just investigate it.

I have been working with the Barts MS group for around eight years and within this time have delivered and been involved in many different projects as a design researcher. Although I am known in the field and at the study sites, in a way I am still an outsider, as I do not have medical training. This enables me the position to ask questions about 'what everybody knows', (Shapin and Schaffer, 1985, p. 6) asking questions about simple or obvious aspects of medical and scientific culture without being thought of as a trouble maker. The pilot studies probe at and investigate some of the taken-for-granted aspects of medical and scientific culture and practice to highlight aspects of **patient experience** that I am researching. The participant groups involved in each study are different. I approach each group of participants myself and invite them to take part in the project, explaining what the purpose of the study is, what their role is and how their involvement would be used. Each study has an activity for the participant to complete, which strikes a balance of being novel, enjoyable and inviting while being able to prompt participant engagement.

The aim of the pilot studies is not to produce information to be analysed. Rather, the aim is to use and deploy them, providing information and insights on the connections of present actors. The activities and associated tools enable playful, explorative responses from the participants that generate new thinking about how patient experience is performed in the clinical encounter, at scientific conferences and through measurement activities. In this way, the pilot studies can be likened to cultural probes (Gaver et al., 2004) which are deployed in the design process to develop unique and often unexpected understandings of a situation rather than produce coherent, generalisable accounts.

Speculative design is a body of work that grounds the practice-based element of this thesis. As a field of design, speculative and critical design marks itself as different from that of affirmative and commercial design in that it is a design practice which does not respond to the practical needs of users and are developed outside the rules and constraints that inform and direct the development of normative commercial products.[3] This design approach creates combinations of obliquely functional objects, manipulated photography, imagery and film to present fictional scenarios to create space for dreaming, challenging

3 Critical design is often connected to the works of Anthony Dunne and Fiona Raby from the Royal College of Art, London (2001) where it was introduced almost fifteen years ago and has continued to resonate by practicing designers and within the design research world. As a previous student of the MA Design Interactions department at the Royal College of Art, these approaches have had a large influence on my design practice and my perspectives on design research.

and debating. The purpose of this is to engage people to explore how the world could be, which in turn aims to highlight problems, complexities and opportunities to move forward. These scenarios are intended to appeal to a broad and diverse audience, and though a variety of contexts such as the general public in museums and galleries or experts working in related fields. Dunne and Raby (2001) suggest that designers can initiate a critical discussion about the long-term implications of emerging technologies, such as nanotechnology and synthetic biology through workshops, exhibitions and publications, which provide opportunities for audiences to engage with this form of design and its ideas. Unfortunately, it is precisely these dissemination formats that have been the focus of much of the criticisms of critical design.[4] However, situated in an emerging scientific discourse and material culture, speculative design (which tends to have a more ethnographic approach through techniques such as cultural probes) seems to have become more absorbed into design research practices. For example, in the *Energy Communities* project led by the Interaction Research Studio at Goldsmiths, speculative prototypes were implemented and installed in users' homes to encourage novel relations amongst participants and prototypes to potentially reconfigure what the very 'fact' or 'problem' might be around issues such as what counts as energy and what actors, communities and issues are involved (Gaver et al., 2015). Michael (2012a, p. 174) describes how these probes and speculative design artefacts seek 'the idiotic'. Michael does this using Stengers' (2005) reflective figure of the idiot, which she adapted from Deleuze. It is also characterized by a 'proactive idiocy' in what he calls 'engagement events' (2012b). The idiot is a designed *object*, responding to events in non-sensical ways, challenging their meanings. So, for example, the idiotic prototypes that were deployed in domestic settings were described as creating inventive problems through participants' responses. Thereby, they were framed not as satisfying human needs but, rather, as designerly ways to frame public engagements around energy-demand reduction. This work reflects the recent growing interest from STS scholars and design researchers to work together to explore the potential of a messier, more material and more speculative process of research, where researchers from both sides show an interest in each other's practices, skills and philosophical offerings.

The main point here is to show how the design of activities, tools, objects and interactions between people, other objects, issues and so on act as creative explorations into emerging issues and situations bringing things about, rather than returning data. The designs in this thesis follow the ethos and practice of speculative design for two reasons. Firstly, speculation can be used as a tool for questioning how patient experience, as a generally accepted fact within healthcare and design, is done to open up conversations

4 Matt Malpass describes how critical design has suffered from oversimplification through its chosen formats of communication. For example, a typical output of a critical design projects is in galleries or magazines, which present the work alongside short captions which in cases have misrepresented the work (2013, p. 335).

about what might be left out through inventive problem making and question how current practices enforce specific kinds of patient experience. And the second reason is to allow the potential of the objects of design to speculatively intervene in clinics, conferences and measurement activities, enabling the possibility of these events to become apparent. This then allows a less human-centred approach to be used for one that is more performative. This thesis aims to contribute how to understand the coming together of entities, people, bodies, knowledge and tools, and understand the potential of the contribution of design to enter into these new relationships. The pilot studies are explained further in the next chapter of the thesis.

Research Study: A Design-led Approach to Explore the Performativity of Measuring Upper-limb Function in MS

The final and substantive method of this thesis is the design of a research study that sets out to develop a new PROM to measure upper-limb function for people with MS.[5] The study brings together people with MS to take part in three research events that are based on the FDA PROM development process.[6] I have already pointed out how the FDA PROM process uses different versions of patient experience (**Experience 1, 2 and 3** and their associated assumptions) to create a reduced list of general measurement activities which further work to distribute versions of **Experience 2.** The research study in this thesis focuses on the situated enactments of MS and goes through the development process, exploring the potential for design methods to create a new PROM and generate alternate versions of patient experience. Going through these stages allows me to study the simplification process that medicine operates in to generate facts of **patient experience** and seeks to creatively explore what new types could be created through the introduction of design.

This research study, focuses on meaningful, situated and interesting activities where people's upper-limb function is affected by their MS. These can be anything, including hobbies, daily routines, interests, desires or wishful activities. The aim is to investigate what happens to the arm and hand function when attempting to complete these activities – what is the combination of bodies, tools, environments and objects that come together in these moments. I use an empirical, situated approach to see what versions of experience and issues come up (Star, 1983, p. 206). This takes the situated action of MS seriously, which has been discussed in the STS analysis of disability studies (Galis, 2011), where disability is an effect of a process of associations in a network. For example, pavements, outpatient departments, medical practices and measurement tools, can all enact action – agency.

5 At the start of this research, I set out to develop a new PROM in the final research study. As we shall see in Chapter 5, this effort proves to be misguided. However in this methodology chapter, I explain the reasoning I used in setting up the study with this original aim.

6 I am describing these as research events, rather than workshops or focus groups to open up the event to consider the performativity of method (Michael, 2012a). The aim is to raise questions about the conditions, procedures and instruments for producing knowledge.

As ANT extends intentionality to non-human entities, I can consider a range of objects and how they perform action. This is a closer consideration of the material politics of design. If fastening shirt buttons and peeling an onion can become enactments of health progression as developed through a system by medical experts, then what would a system of measurement look like if developed by people with MS? What if other instruments are used for producing knowledge?

These activities are recorded and collected through a combination of participant insights and comments, along with observations of physical demonstrations of the activities. With the participants, we investigate what measurement means in the context of each everyday activity to develop some form of understanding of how it is completed for different people in different contexts. Introducing objects into this discussion enables people to take a new perspective on the measurement activity, triggering reactions, affects and responses to the activities. This is a re-imagining of the measurement activity where there is an openness and playfulness to prompt participants to share unexpected rationalities. This builds on insights from the pilot studies where the reactions and actions of both the participants and the researcher contribute to the performative effects of a design. The research events are settings for a generative collaboration between myself, the participants and the interaction of objects (tools, setting, environment) present to create a space for new versions to emerge. The three events are held in a non-medicalised setting as I am particularly interested to find out what versions of experience can be made without the inclusion of medical spaces, equipment and assumptions. This is an opportunity for the patients, bodies, tools, objects and activities to come together and co-become, changing in this process.

At the simplest level, this process gathers a range of activities that affect the upper-limb function of people with MS that are meaningful to them in their daily life, rather than activities that are statistically meaningful to medicine. I imagine this to be a contribution to the existing ABILHAND tool which requires its current activities to be updated for people with MS (Penta et al., 1998; Barrett et al., 2013). However, I aim for something more radical in both its format and its function.

In the responses and reactions from participants, I am not looking for patterns or solutions, but specificities that can be developing into what I originally intend to produce, a new PROM to generate new and different versions of patient experience. I am looking to explore the potential of creating an alternative PROM tool that is not limited to producing numbers (**Experience 2** like current PROMs). But, rather, generate, or script, more inventive and playful activities to measure upper-limb function and other versions of patient experience. The format this takes – digital, video or instruction manual – is unknown. However, it is a more engaging material object than the existing paper-based questionnaire. This acts to reframe the measurement activity not only as something that is done to people with MS but rather as something that also is more participatory and engages other actors.

Involving patients in research activities

This research is part of a part-time PhD registered at Goldsmiths, University of London, so it must comply with the University of London ethics procedures. As it also involves people who are patients of the NHS trust that this research is linked to, it must have successful Health Regulatory Authority (HRA) approval. This is the process for research conducted in England with the NHS trust that assess the governance and legal compliance of the research. I will discuss the ethical issues around this work shortly. The implication of going through this process is that specific research procedures that apply to medical research must be followed. This involves producing a protocol document (see Appendix C) which sets out the procedure for conducing the research, including information on the sampling decisions, consent process, dissemination plan, confidentiality and data storage.[7] There is an increasing number of design research projects that engage with HRA approval procedures which also aim to explore aspects of design research (Bowen et al. 2010; Macdonald 2013; Neves 2014).[8] This engagement with the practical procedures increases the accountability in the positioning of the project as design research does not have authority in medical research since it is from a different field. This is an important point for practitioners working with patients in a healthcare context, or those that would like to establish themselves as a researcher in this field and have impact within it. It involves strict and rigorous regulations and is a time-consuming and complex process to complete as part of a PhD. I have previous experience putting together and delivered previous research involving the deployment of design tools within a healthcare study (Thomson et al., 2015). This experience highlighted strengths, limitations and opportunities within the medical research process for design-led research to further explore, interrogate and make proposals around the assumptions of involving people in research. This also allows me to further explore some of the assumptions that are inherent in the process, for example, the way patients are produced within the

7 Operational documents, like the study protocol are more frequently encountered in medical research than design (Berg, 1997; Timmermans and Berg, 1997; Berg and Mol, 1998) where its aim is to outline the procedures of the research study, or bring order where there is disorder (Berg and Mol, 1998, p. 228). The protocol can also be thought about analytically as a technique, or a tool that embodies of script of how the research event is supposed to be implemented with delegated roles and tasks for researchers, patients, healthcare professionals and ethical committee members (Akrich, 1992). The protocol is a sequenced description of how to act in each situation of the research study. Although it is a written text, it affects peoples work and as I attempt to argue, contributes to the definition of versions of patient experience.

8 This point is in comparison to design projects that engage with healthcare but under a consultancy model such as those ran by the Design Council, Think Public, Helen Hamlyn Centre at the RCA and also projects produced from the hybrid design and healthcare space, the Helix Centre. Problematically, all too few design projects are asking questions of what types of research we are enacting and how we intervene through the design projects and proposals.

medical research process and the limited role ascribed to patients in the process of being either research *subjects* or *participants*.

There are two reasons for choosing to conduct this research.[9] Firstly, practically, contribute to the field of practice-based design research within healthcare. Secondly, it enables me to highlight assumptions about patient experience in the medical research process. Patients are currently involved in the research process through patient public involvement (PPI) activities.[10] These have traditionally been considered activities that increase trial recruitment. However, now PPI activities are working towards being more participatory, empowered roles for patients in the research process. Levels of participation in PPI projects are commonly categorised using Arnstein's (1969) ladder of participation, ranging from no participation and tokenistic involvement to full participation. More participatory activities would be patients contributing to research studies steering committees, analysing data and contributing to writing up the research. Unfortunately, these are difficult to achieve with most PPI activities that are actually carried out being criticised as being tokenistic formats of involvement (Buck et al., 2014). However, considering the assumptions of **Experience 1** and an ANT-informed understanding of participation (Andersen et al., 2015), these levels are ascribed through subjective intensions both from participants and those leading PPI activities. Whereas, ANT is concerned with things in the making and so enables me to look beyond the participation of specific and solely human actors, and see participation as an achievement of a network with performative effects.

Further criticism of existing PPI activities is said to be about the lack of theoretical consideration about the ways that patients are included in research activities and the lack of analysis of the epistemological implications of these modes of engagement (McKevitt, 2013; Boaz et al., 2016). For example, focus groups are a popular method to gain patient opinions on topics of potential research in the grant-writing stage and frequently used to evidence PPI activities. Lezaun (2007) describes how the group dynamic is used to bring relevant opinions into existence. Focus groups which originated in business and were used to obtain a range of opinions on products with the goal of enhancing marketing strategies (Krueger and Casey, 2009). Where a selected group is brought together with the goal of getting the individuals to share ideas and perspectives by asking them questions to start the discussion. Yet, further literature describes focus groups as *technologies of elicitation*, a term I will explore

9 Research activities within medicine and healthcare that involve human participants can be described in different ways. Clinical studies, sometimes called clinical trials for example, are where participants are assigned specific interventions according to a research protocol. Observational studies are where participants are not assigned to specific interventions and the group is observed. But there are many other types. Common to all these studies is their aim to answer specific questions on how to prevent, diagnose and treat the participants that are involved in the study. There is no clear definition of a research study, but I would describe it as the recognised procedural process, involving established research methods, of developing new knowledge within healthcare.

10 INVOLVE are a national advisory group set up by the Department of Health who promote and support public involvement at every stage of the research process. They have published widely in this area, including guidance on planning, managing, designing research instruments, undertaking, analysing, writing, disseminating and implementing research.

further in Chapter 4, as they empower the agenda of the researcher. These assumptions of participation have not been problematised in the field of PPI. Design that engages with the politics of knowledge production, as influenced from fields such as public engagement in science, has an opportunity to engage patients in research in novel ways. Therefore, there is an opportunity for design research that has a performative understanding of method and an awareness of the assumptions of patients' experience to contribute to the field of PPI empirically and theoretically.

Research Participants

Participants that are invited to take part in the research study are people with MS and healthcare professionals (neurologists, occupational therapists, MS nurses). These groups of people are involved in this study due to the type of knowledge they can potentially contribute in an attempt to provide a symmetrical approach to engagement. The involvement of people with MS in the research process is due to their embodied, practical knowledge of MS. I describe it as knowledge rather than experience of MS to try and avoid picking up some of the assumptions surrounding the use of experience that have already been highlighted in the literature review. Unlike scholars associated with public engagement in science, I do not describe it as 'lay opinion', which stands in contrast to an expert opinion.[11] Ives et al. (2013) point out that as people with lay knowledge become more involved in the research process, they ultimately lose their 'layness' and become 'tamed' (p. 3), therefore becoming unable to remain objective of the process they are involved in. Instead, involving people in contributing their embodied knowledge attempts to keep an empirical focus on the study while also following the participatory design tradition and identities, and recognises people as competent practitioners (Suchman, 2007). Within this project, they are competent practitioners, as they contribute their knowledge of day-to-day situations where MS affects them in the home.

This study invites people with MS who suffer from problems with their upper-limb function and generally have the progressive form of MS either PPMS or SPMS. This type of MS is characterised by having a persistent increase in disability, where other forms of MS will have plateaus with periods of not getting worse. People with SPMS and PPMS will usually have walking difficulties and rely on either a walking aid such as a stick, a walker or be in a wheelchair. Until recently, the treatments that have been developed for people with MS have focussed on people with the relapsing form of the disease, as it was considered that once a person had gone onto the SPMS and PPMS stages, they could not be helped by treatments. Now there is an argument to save as much function in people with MS, regardless of the fact that they are already in a wheelchair (Giovannoni et al., 2017). But the

11 Ives et al. (2013) describe the importance of the lay opinion within research processes as it brings the opinions and experiences of illness and service use of 'outsiders' into the research process.

problem, that has been outlined in the literature review, was illustrated in the ASCEND trial, where treatments are not considered to help improve (or save!) function in SPMS and PPMS as the outcome measures to measure and prove the improvement of taking the treatment all focus on walking distances. The ASCEND trials showed an improvement in upper-limb function through using the 9-hole peg test.[12] This calls for a more sensitive and realistic measure of people with MS's upper-limb function.

Clinicians are involved to contribute their practical knowledge of MS from medicine and their understanding of the body. This group involves one MS specialist occupational therapist and one MS specialist neurologist, Gavin Giovannoni (Professor of Neurology), to ensure that the study is designed and carried out with interest and relevance to the field of MS while also ensuring the ethical conduct of research. My role in the research study is as the principle investigator, which has responsibilities for designing the research study, completing the procedural ethical requirements, recruiting for the study, managing the research team and managing logistics (patient travel, funding, room booking, catering). The research events are facilitated by Harriet Smith, a collaborator from my previous work, who is also a professional facilitator and a person with MS; therefore, she has a skillset that can facilitate the session and contribute to the suitable set up of the sessions.

Measuring upper-limb function in MS

The procedure follows the standard stages of the PROM development process as set out by the FDA, focussing specifically on item generation and selection, developing a scale and testing (U.S. Department of Health and Human Services and Food and Drug Administration, 2009). The aim of the research study is to develop a new PROM to measure upper-limb function for people with MS. The current PROM that is used to measure upper-limb function is the ABILHAND questionnaire shown in Figure 20 (Penta et al., 1998). It lists 56 questions which measure manual ability (defined as the capacity to manage daily activities using the upper limbs, regardless of the strategies involved) and asks patients to record on paper by making an 'X' on a Likert scale of difficulty, ranging from 'Not at all' to 'Extremely'. The results of all of the questions are given scores so, when summed up, a total score is produced which is used to measure the variable upper-limb function. The questions that are asked are considered measurements of the variable, upper-limb function. The appropriateness of this measure has gone under scrutiny recently as it was originally developed to measure people recovering from stroke and was not developed with psychometric measures. This work highlights the need for extending the scale in two ways (Barrett et al., 2013). Firstly, by adding tasks that are more difficult than question 16 (threading a needle) and easier than question 14 (washing your hands). Secondly, it was

12 For a full comparison of upper-limb function measures, see Lamers and Feys (2014).

ABILHAND - Manual Ability Measure
English version

Patient _____ **Date** _____

	How **DIFFICULT** are the following activities?	**Impossible**	**Difficult**	**Easy**	**?**
1.	Pulling up the zipper of trousers		X		
2.	Peeling onions	X			
3.	Sharpening a pencil		X		
4.	Taking the cap off a bottle		X		
5.	Filing one's nails				X
6.	Peeling potatoes with a knife		X		
7.	Buttoning up trousers	X			
8.	Opening a screw-topped jar		X		
9.	Cutting one's nails				X
10.	Tearing open a pack of chips			X	
11.	Unwrapping a chocolate bar			X	
12.	Hammering a nail	X			
13.	Spreading butter on a slice of bread		X		
14.	Washing one's hands			X	
15.	Buttoning up a shirt		X		
16.	Threading a needle	X			
17.	Cutting meat	X			
18.	Wrapping up gifts				X
19.	Fastening the zipper of a jacket		X		
20.	Fastening a snap (jacket, bag, ...)			X	
21.	Shelling hazel nuts				X
22.	Opening mail				X
23.	Squeezing toothpaste on a toothbrush			X	

Université catholique de Louvain, Laboratory of Rehabilitation and Physical Medicine order 1

Figure 20 The Abilhand Questionnaire listing the upper limb activites that are currently measured in people with MS by the clinical team.

described that there is a need to make the activities more relevant to people with MS, as the activities listed on the questionnaire are not specific to the condition.[13] Through the three events of the research study, participants propose new *items* to include in this new scale and measure that are both more relevant to them, and better measure their capabilities.

Activities

The three research events take place two weeks apart and each last three hours in total, with comfort breaks throughout. The three-hour session is structured around a number of group activities that are encouraged and supported by objects displayed in the room. Each event begins with a welcome from the facilitator and a description of what is about to happen.

The new items are represented through objects which invite participants to take an active role in contributing their knowledge to the study while also being designed in a way that allows non-humans opportunities for agency. The use of objects, tools, props or probes in design activities has been widely used in design research.[14] Ehn and Kyng (1991) describe how the use of prototypes of rough materials such as foam, cardboard and clay can create a language where everyone in a workshop can share. Other tools such as probes (Gaver et al., 1999; Mattelmäki, 2006) or design games (Brandt, 2006) can engage participants to experiment and explore new possibilities. Figure 21 illustrates and explains the three stages of the research study.[15]

Involving objects to represent activities recognises the performativity of design and moves on from Butler's performative understanding of language to involve thinking about the material agency of the tools and activities that are involved in the research events. These have been described as co-agents in performative acts (Anderson, 2006) where, in a way, we can create what we study through the design of activities, taking into account our knowledge practices and their capacity and involvement in making knowledge. I aim to work with this productively, in choosing to study patient experience through upper-limb activities positioned around activities of measurements which celebrate situated interactions to bring about interesting future experiences.

13 In an article on the Barts MS research blog, people with MS suggested activities of popping a pill packet, picking their nose, playing dominoes and bum wiping as example activities that are affected by difficulties in upper-limb function (Giovannoni, 2016). These were in response to a blog article about the limitations of the ABILHAND questionnaire to capture activities that affect people with MS.

14 Cultural probes are starting to be adapted and used by health researchers and applied within healthcare contexts (Wherton et al., 2012). This has sought criticism from designers as a misappropriation of the core principles and values of the technique and described as a discount ethnography (Boehner et al., 2012). Therefore, it is important that I am clear of the purpose of these explorative tools and what they contribute to the research activity.

15 Figure 21 is itself an immutable mobile in how it renders the research event as flat and contrivable (which I know it is not). This illustration has been produced to describe the procedural process of the study here in this thesis and also for the ethical planning process.

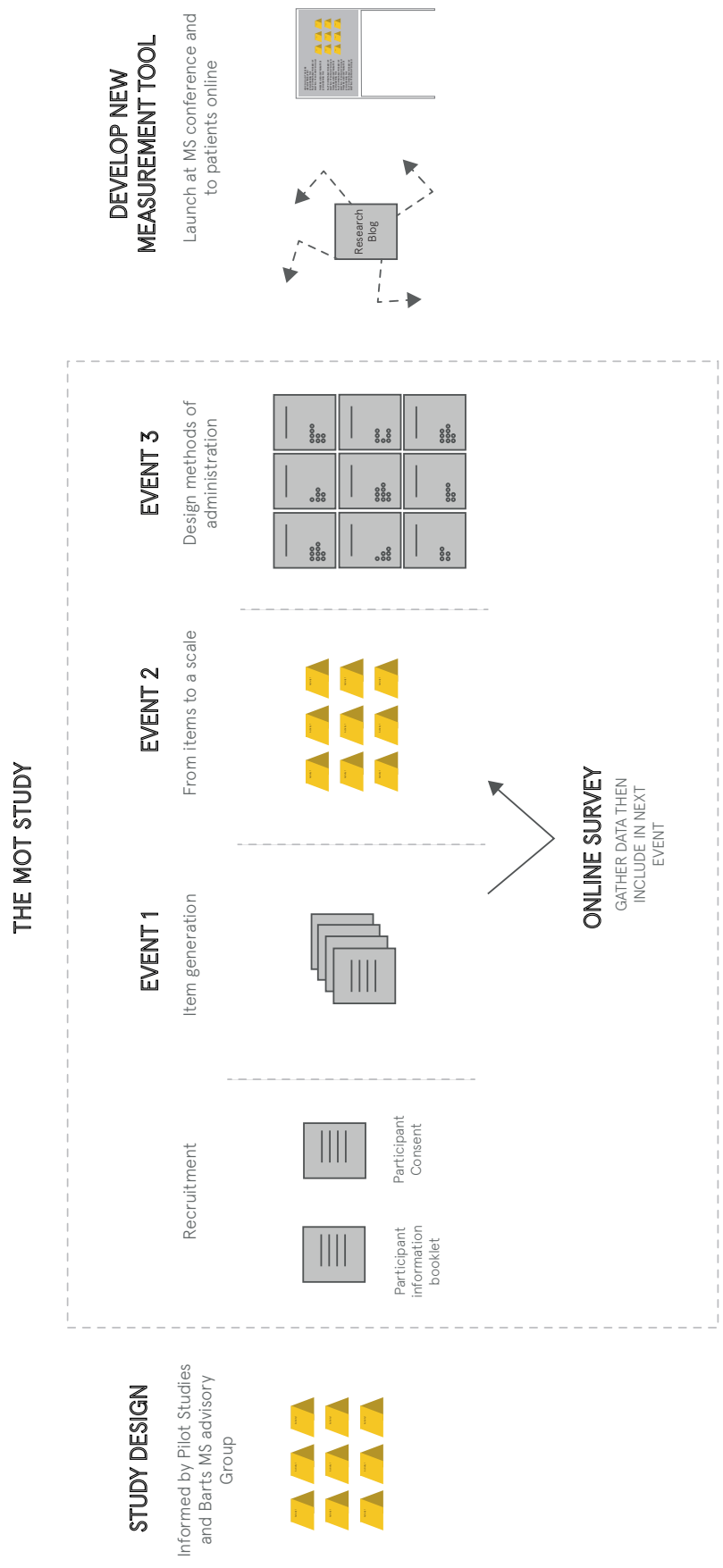


Figure 21 The MOT study process

Removing assumptions

The research study is held in a private meeting room in a venue at the Olympic park, Stratford, East London. The main reason for this is that it is a neutral environment which does not prioritise any of the participant groups (i.e., it is not a clinic space). This physically removes the participants from the hospital space with medical devices and sterile flooring and reduces the chance of interruptions by clinical colleagues. Similarly, all participants have to travel to the study venue, which is a journey to a new space rather than their regular journey to work, or journey to a hospital appointment. The material environment can have an enabling or disabling role and play an important part of interactions, as Pols (2005, p. 212) describes how hospital spaces can influence how and if appreciations are enacted. It is hoped that this material engagement moves participants beyond categorised roles of 'patient', 'researcher' and 'clinician' that are ascribed to people in professional, hospital and research contexts to enable them to explore different or alternative roles.

Recording

Within the research study, I take on an analytical role to observe the research events. This is a form of participant observation, a data collection method most commonly used in ethnographic studies that has been adapted by designers.[16] Design-led approaches to participant observation differ from the more social science or anthropological approaches where descriptive accounts are produced and analysed via formally recognised means. When designers directly observe social situations, they do this with the aim to not produce 'good' descriptive accounts, but to produce insights for the design activity.

Within the research events, I focus on the empirical interactions between human and non-human actors, their orderings, disorderings and effects. Also, by tracing how things go wrong in social processes, we can trace how non-humans play their part (Michael, 2004, p. 6). I document the reactions and actions of the participants through sound recording and hand transcription (Appendix A), note-taking (Appendix B) and still photography. I focus on the 'liveness' of the research event, reporting on the heterogeneous network of actants that are brought together and their agency. I also include non-humans into the analysis in a

16 Ethnography is a methodology that originally developed within anthropology where a researcher aims to produce descriptions of people's practices and interpretations of their meaning by becoming involved in their everyday activities (Blomberg et al., 2003). 'Traditional' ethnography is often seen as difficult to integrate with design processes (which are deadline-driven, or play a smaller part of a larger design activity) as ethnography is intended to be a 'prolonged activity' over several years, and produces findings that are often long and discursive (Hughes et al., 1995). As a result of this, several forms of more flexible approaches to participant observation have developed that provide designers with valuable insights into the perspectives and experiences of those they are designing for. 'Design ethnography' (Salvador et al., 2010, p. 36) or 'quick and dirty' ethnography (Hughes et al., 1995) is where short, focused studies are conducted to quickly gain a general picture of the research setting. These approaches are used within academia as well as industry, with IDEO developing 'corporate ethnography' (Suri and Howard, 2006) for manufacturers to aid product development and evaluation. Here, the approaches focus on portions of contexts and patterns of everyday life that are deemed important to inform design, instead of attempting a comprehensive understanding of a context. Yet, it is for this reason that designers have been criticised as not being suitably qualified to produce an understanding of a context as they develop bias understandings with superficial overviews and lack analytical sensibilities.

way that does not imply dichotomy of human/non-human, subject/object (for this Michael proposes the term co-agent [2004, p.19]).

Following the critique of performativity through the lens of event, it becomes much more difficult to identify where agency is happening. I expect that some of the performative effects are analytically unavailable, and for others access is not be possible (for example the effect of drug users as described by Gomart and Hennion [1999]). The point here is that events occur outside of the control of any single actor and the effects of this is unknown and unknowable. Therefore, in an attempt to record non-action, I sound-record, note-take and capture still photography where necessary to capture how the activities unfold.

Consent

Conducting any form of research involves ethical procedures that need to be followed to ensure that the research is carried out in a procedural and ethical way, but delivering a study within a healthcare context involves an extra level of contractual and procedural processes. This thesis is based within the design department at Goldsmiths, and the practice-based element, the pilot studies and the research study situated within the Barts MS research team at QMUL. The people involved in this research are clinicians (neurologists, occupational therapists, clinical researchers and neuroimmunologists) and patients (people with MS) who are invited to take part in the research activity from the Barts health NHS trust. Therefore, I gain informed consent from all of the participants involved.[17] A participant information sheet explains how their involvement and information shared in the session is used, what to do if they would like to withdraw from the study and confirm, for the patient participants, that their clinical care is not affected by their involvement. There is no formal ethical approval in place for the pilot studies as they are linked to service-improvement activities related with my professional role within QMUL. All participation in these studies, and the research study, is voluntary and confidential where no data collected will make it possible to identify any individuals.

In regard to anonymisation throughout the thesis, I have changed the names of individual patients, but unlike other studies of healthcare groups in sociology (Berg, 1996; Singleton, 1998; Mol, 2002; Pols, 2005) or in design (Danholt, 2008; Wilkie, 2010), I do not anonymise the locations or institutions. The reason for this is that the work is practice based and will be in the public sphere associated with my name, and so would be easy to find.

17 Medical research ethics were put in place after the horrific treatment and experimentation of the sick and other groups of people carried out in the medical institutions of the Third Reich's Universities, hostels and concentration camps. After World War Two, this led to the development of principles intended to regulate the relationship between patient and doctor, science and subject. The key to this relationship was the recognition of the right of the patient, or the subject, through the principle of 'informed consent', which is a contractual agreement and understanding of what their participation will involve.

Ethical considerations of methodology

This design research engages in the practice of medical measurement of individual's physical disability and chronic illness progression, investigates practical activities that are conducted between healthcare professionals and patients, and attempts to have a closer look at how MS is enacted in people's lives. I use explorative design research methods that are inventive, and where I am even unsure of the effects of their deployment, in that they can bring some things into being over others. There is no standard design-led research procedure for navigating this complex situation, so I must take on, re-design and adapt current health service research procedures to make this work, and conduct responsible and accountable design research. In light of this, the study does not necessarily encourage the involvement of newly diagnosed patients. I also acknowledge and am aware that people with MS are coming together to share their thoughts and feelings about their care and life living with MS, including potential private and upsetting stories. I treat all of these contributions with the greatest respect and can provide details of further sources of support if this is necessary. There are more details on this process in the MOT study protocol in Appendix C.

Reflexivity

In most research methodologies, interfering with the object of study constitutes bias. Hence, researchers are encouraged to account reflexively for their biases in order for others to evaluate the knowledge claim. The idea of bias is significantly reconfigured when drawing on STS and understandings of performativity where the possibility of obtaining unmediated access to an 'objective world' is disregarded.[18] Further, this idea needs to be extended with practice-based design research that aims to intervene in the world it aims to study, in one way or another. Therefore, the concern of bias changes and becomes somewhat irrelevant as it presumes that research should be conducted out with limitations of interventions and perspectives.[19]

This is of particular interest to practice-based design research that focusses on physical interactions within the world which, in my case, are embroiled with the researcher's involvement in the research setting. Through my research, I am not aiming to produce pristine objective descriptions of the world and the research context.[20] Instead, using a performative understanding of research, I consider the instruments, techniques and representations, considering how they enable knowledge to be produced. Following

18 For critiques and further unfolding of the problem and implicit assumptions of reflexivity, see Latour (1987) and Barad (2007).

19 As previously mentioned in the literature review, Haraway (1991) points out how some accounts of STS researchers tracing techno-scientific networks do not include accounts of their own participation and influence in the construction of knowledge and can be likened to a 'god trick' with their view of the research as from above looking down.

20 This is related to the criticisms of design approaches to ethnography which suggest that designers do not observe in such a way as to minimise their influence, and that any understanding they develop is biased, subjective and not formulated according to any formal analytic techniques. In order to clarify the role and influence of my subjectivity in this research, I include evidence of my research development process in the accounts of the pilot studies, the study development and as documents in the Appendix of this thesis.

STS, a central contention is an appreciation of those instruments, apparatuses, theories and representations, since they are practices through which the world is cultivated and performed.

When writing up my account of the research events, I include descriptions of my involvement to attempt to provide a reflexive account. For this, I draw on Latour's 'infra-reflexivity' (1988, p. 169) and Donald Shön's (1983) reflexive practitioner to make clear how my accounts of the research texts are produced. The notion of the reflexive practitioner, and extension to the reflexive designer, produces accounts of design that are situated and emergent through the thesis and made valid for design research. Michael (2004) describes this as being a co-agent where the researcher is situated, embodied, emergent and embroiled within the range of actors present.

In this research, and for this thesis, I am telling the stories of the research, so I am aware there is a certain impossibility of symmetry as I provide an account of the research from my perspective as a human actor and a feminist design researcher. In relation to providing reflexive written accounts of the research activity, there are three main formats that are produced: the analytical and theoretical descriptions in reference to the different perspectives set out in the literature review and methodology chapter; practical and operational descriptions of the research study in the study protocol informed by medical research to comply with the HRA process; and another account for participants in plain English describing their involvement in the study, what information is gathered and how it is used.

Conclusion

In this chapter, I have outlined the methodological rationale I have developed to study a performative understanding of patient experience. I have also discussed the key issues and challenges involved in working with patients in this research. I described how patient experience can be studied as a performative, emergent phenomenon in a design-led research process involving pilot studies and research events. To do this, I argue that these forms of inventive methods are necessary to explore the potential for studying something that, I argue, can have no visible effects. This equips me with an empirical approach for exploring and understanding the PROM development process, and how different versions of patient experience are brought about, can co-exist and can also be made *through the introduction of design*.

Chapter 4: Opening up technologies of experience through three pilot studies

This chapter starts with a question: what kinds of technologies are at play in the doing of patient experience? I ask this question to open up the locked-in world of patient experience as a given, or an existing, authentic truth that is considered available to be acted upon, measured, designed and improved. Therefore, experience-in-the-making affords an opportunity to investigate the performative activities through which different versions of patient experience are currently accessed, captured, measured, defined, reproduced and circulated. In studying how new versions of experience emerge, I will draw on the table of experience developed in the literature review that put forward many different versions of experience from different writings in recent science studies, medical sociology and design practices. These different versions pose problems and challenges for the potential for working with new and different versions.

This chapter presents and reflects on three pilot studies where practice-based design interventions are deployed to investigate situated circumstances in which approaches to patient experience might be re-thought within three distinct contexts of an international academic medical conference, of a neurology outpatient clinic and in a clinical measurement activity between a clinician and a person with MS. The pilot studies aim to rethink how patient experience is done in these settings through considering how slowing down the processes by which experience is grasped can thereby open up ways of understanding other kinds of experience that are being ignored and screened out, as well as the possibility of determining new kinds of experience. I am interested in how techniques of experience measurement can be rethought as the situated enactments of experience rather than the generation of cleaned-up versions. Finally, if I slow down experience-in-the-making, I can also appreciate how the exchange of other objects, or *experience phenomena*, might be understood as another example of situated experience that gets screened out of measurement practices. Once sensitised to new versions, it becomes clear how new versions of experience can be located, how they operate and how they circulate in contrast and amongst other versions. But before this, I include a brief survey of the literature that I will draw on throughout the rest of the chapter and a description of the use of pilot studies in design-led research.

This chapter is organised backward, flipping the traditional order of conventional research processes. It starts with dissemination, then considers processing, and ends with capturing patient experience. The intention is to discover how new versions might operate away from existing assumptions and unlike other forms of knowing. The chapter concludes with some reflections on how the pilot studies sensitised me to different contexts where new versions of experience might be identified, traced and potentially better understood.

Technologies of experience and slowing down

Technologies of (patient) experience work to capture, record, process, format and circulate patient experience as different versions – in other words, instruments and technologies

of experience produce experience. The term can be traced back to Paul Ellwood's 1988 article in the *New England Journal for Medicine* which outlines the introduction of outcome management after the US health reforms in the 1970s. These are 'designed to help patients, payers, and providers make rational medical care-related choices based on better insight into the effect of these choices on the patient's life' (1988, p. 1556) bringing together multiple concerns from the US health system linking health outcomes with financial interests. In the context of patient care for people with MS and upper-limb function, the impact of this view can be evidenced today within the NHS with a wide range of subjective measurement tools such as PROMs (described in Chapter 2), as well as objective measures such as the nine-hole peg test (Feys et al., 2017) and the Box and Blox test (Platz, 2005).[1]

I want to draw similarities between Ellwood's call for the development of outcome measurement as critical for physicians to remain in control of their profession (Sullivan, 2003) and Lezaun and Soneryd's (2007) framing of technologies of elicitation in the study of public consultations in PUS. Public consultations, research interviews (Jerak-Zuiderent, 2015; Mazanderani and Paparini, 2015), opinion polls (Osborne and Rose, 1999), home interviews (Callon and Rabeharisoa, 2004) and focus groups (Lezaun, 2007) are framed as techniques to capture events where experts are brought together with devices and instruments to make communities real for the productivity of interested parties as they 'generate lay views on the issues at hand' (2007, p. 279). Further ethnographic work by Vinh-Kim Nguyen (2010; 2013) draws on Foucault's notion of 'technologies of the self' (1988). In it, Nguyen looks at peer support, counselling, participatory research and public testimonies as 'confessional technologies' (2013, p. 440) in a performative approach to knowledge practices of HIV in Africa. These all raise epistemological and ethical questions about the use of different technologies as a means of accessing and producing knowledge of people's experiences.

In this chapter, I argue that technologies of experience are important theoretical sites for feminist technoscience studies because of how the materiality of bodies, roles and knowledge are positioned as matters of fact and 'do-able' (Fujimura, 1987), by scientific practice and medical work.[2] This thesis takes a material-semiotic perspective developed by ANT (Haraway, 1991; Law and Hassard, 1999; Latour, 2005), which views material objects, tools and bodies, as active participants that shape human bodies as part of heterogeneous networks creating new practices and knowledge (Ruppert, Law and Savage, 2013). Here, I use a broader definition of technology. Therefore these technologies, even if they are as simple as chairs around a table, measurement tools, or conventions in interactions, are used across health services, national trials and research studies in the form of PROMs

1 A concise overview of outcomes measures related to upper-limb function in MS can be found in Laymers and Feys (2014).

2 Casper and Berg (1995) make similar points in their analysis of developments of sociology of medical and scientific work. Interestingly, they call for more communication between the sociologies of science and medicine when considering this field of study.

(Giovannoni, 2017), patient experience surveys (Barts Health, 2018), self-monitoring apps (Roche, 2018), PPI initiatives (Thomson, 2014) and patient registers (Osborne et al., 2013) contributing to the creation of large-scale data collection, aggregation and quantification of different forms of experiential data. This shows socio-technical progress towards measurement-based medicine where medical data is assembled online on websites such as Patients Like Me (Scanlon, 2013).

Patient experience metrics, such as the distance a person with MS can walk (which is considered an important indicator of the health of a person's neurological system), can be sorted, combined with other people's data and compared and re-assembled through different categories of type of MS, EDSS score, month and country of birth, creating 'population objects' (Ruppert, 2011, p. 219). This, along with other data, is used to generate a variety of predictions about that person's current health, including their disability prognosis, their response to treatment (along with assumptions about their personal relationships) and their occupational future. Used in this way, these technologies have direct impact on the lives of those with MS, as shown with the recent personal independent payment (PIP) walking criteria change from 50 to 20 meters. This is crucial because the dependence on walking criteria effects how MS benefits are calculated, with a miscalculation reducing or even stopping weekly payments to people who greatly need it.[3] Described by MS charities as 'senseless criteria' (Wetherly and Erez, 2018, p. 28), it raises many questions about the nature of the knowledge generated by these technologies of experience, as well as the influence of market forces and healthcare-provider incentives in the production of metrics.

Isabelle Stengers' notion of slowing down (2005) is a helpful tool to question the role of technoscience and expert knowledge in shaping contemporary worlds. She introduces the idea of slowing down thinking and decision making in the context of experimental scientific research, but it also has important implications for researching patient experience through design research. The implications for patient experience would stop experience from being seen as a resource that can be exploited for the sole benefit of research or service development and would create opportunities to engage with the uncertainties of human (patients, researchers, designers) and non-human (measurement tools, research objects, scientific processes) entanglements. Specifically, this enables me to think about whose interests are being fulfilled or suited in the way that patient experience is currently researched and produced, allowing me to question the influences of healthcare policy (WHO, NICE, NHS trusts), research funding and agendas (set by MS charities, research councils, national clinical guidelines) or the pharmaceutical industry in the production of, what Stengers describes as, fast science. This is an opportunity to develop an awareness

3 The PIP is the new disability living allowance which calculates how much weekly financial support a person with MS should receive. The new PIP guidelines introduced in 2013 use the 20-meter walk test to determine how disabled a person is and has received negative feedback from charities, healthcare professionals, patient groups and their families.

of the particular and selective thought style of researchers and clinicians in the field of neurology and MS.

In this chapter, I embrace this call for slowing down and apply it through design research in a practical way. In the presentation and analysis of the pilot studies, I consider what happens when working with patient experience is slowed down. It then becomes possible to pay attention to the things that are not counted or included in the scientific and medical methods of doing patient experience. Slowing down through design research will enable me to look and learn from things left out and consider if what they fail to capture is interesting, useful or important. So, an important question at this point in the thesis is, what can design research aimed at slowing down tell us about technologies of experience and experience in the making?

This engagement with patient experience could be a way to perform different versions of patient experience as an opening that slows down thought and potentially generates new possibilities, rather than researching what does, or does not, already exist as found objects of **Experience 1**. This call to slow down is not about offering another solution. Instead, it enables an opportunity to rethink how patient experience is done and opens up new ways to explore differences. It creates opportunity to arouse a slightly different awareness of the problems and solutions around us. This important point effects the analysis of all three pilot studies, as firstly it slows down the creation of the material things (Bingham, 2008) such as scientific posters, research abstracts and emails between colleagues, which have important performative effects in the circulation of new versions of experience. Secondly, bodily practices become settings where things get slowed down, such as how walking can embody what Stengers (2005) calls a politics of slowness. Existing scholars looking at walking methodologies consider the human walker as the animate agency on a walk (Springgay and Truman, 2017) creating space for hesitation and resistance, producing new modes of relating. This enables me to think about what else is happening in walking activities.

The pilot studies slow down and open up the chains of translations, or how different actors form different networks (Callon, 1986) involved in the construction, or enactment, of new patient experiences. The translation and inscription process, or simplification work (Star, 1983), of scientific and medical research transforms one version of experience, **Experience 1**, to another, **Experience 2**, and then inscribes it in a specific format of the poster as a result. In other words, this is experience as immutable mobiles (Lynch, 1985; Latour, 1987). Meaning data versions that are mobile, in that they can be shared while also remaining unchanged, can be used as evidence in scholarly papers, reports and posters adhering to demanding standards about their reliability. As interventions, the pilot studies propose different forms of interaction amongst different actors and material forms – or inscriptions (Callon, 1991, p. 143) – and the researcher. By slowing down this process, the possibility of translating and inscribing in unexpected ways becomes possible. This

supports the argument that patient experience is precisely what emerges out of the chain of translations, or technologies of experience, that produce it.

Slowing down can also help understand not only planned interventions but also responses from participants. Stengers' figure of the idiot (2005), taken from Deleuze, is a helpful analytical tool to interrogate the implicit assumptions about patient experience and the way it shapes existing arrangements, relationships and interactions in specific settings. This makes it possible to be more sensitive to the ways in which particular identities and participant reactions emerge, as well as understanding the role of design research in the context of MS. Michael (2011) uses the conceptual figure to describe how speculative design experiments in public engagement activities can idiotically affect the sense of what constitutes a piece of research material. The idiot, as well as the practice of pausing and reflecting, helps think through what is known, what is not known and what cannot be known. Here, I am looking to see how the pilot studies work within and also overspill the framing of existing measurement procedures, dissemination events and clinical encounters to question whether I can know what is going on and, in this case, whether experience is really being captured.

In this chapter, I bring the notion of slowing down to experience technologies to analyse the knowledge production process and practices around it. Technologies of experience process, format and produce taken-for-granted versions of experience, arguably speeding up the process of patient experience generation and circulation for the purpose of external actors, such as commissioners, health trusts, funders and regulators. Through this research, I am intentionally intervening and disrupting this process, slowing it down both in thought and in practice. This will have implications on how it results in everyday contexts.

Pilot studies as part of design research

The short practice-based pilot studies described in this chapter are experiments where I use design to investigate patient experience in three distinct contexts: an international academic medical conference, a measurement activity and a clinical consultation. Within these specific settings, there are many different opportunities for design to intervene and a number of different roles that design could take. Design is frequently positioned or implicated within healthcare as contributing to increasing efficiency and productivity, reducing error (West et al., 2014), improving care (Donetto, Tsianakas and Robert, 2014) and ultimately improving experiences. However, this thesis problematises this positioning of design in relation to generating and altering pre-existing experiences. So, it becomes a balance between problem solving and more playful explorations to open up valuable new directions (Pullin, 2009) when working as a designer within healthcare. I suspect that by slowing down design's involvement in healthcare will enable design researchers to think beyond 'doing good' and spend more time thinking through how else design can contribute

to new notions of patient experience.[4] To do this, design work needs to be relieved from the reductionist constraints and limitations of solving problems so that design exploration can disrupt, react and provoke reactions which otherwise would not come forward (Danholt, 2008).

Pilot studies are frequently used when designing clinical research to evaluate feasibility, efficiency, accuracy of measurements, recruitment and outcome rates, and effect sizes to improve study design prior to performing a full-scale research project (Hulley et al., 2007; Thabane et al., 2010). For example, in a pilot study looking at how feedback from patients can improve nursing care, the study provided evidence that conducting surveys on hospital wards via staff was a feasible approach to gather patient experience data (Reeves, West and Barron, 2013). The study could then deliver a phase-three, randomised and controlled trial using this approach. Considered as preliminary tests, pilot studies are particularly helpful to the overall research process for new interventions when the risk of failure is high but the value that they bring in exploring the unknown is worth this risk.

In design practice and research, activities of testing and iteration are described as workshops, probe activities (Gaver, Dunne and Pacenti, 1999), prototypes (Wilkie, 2013) and storyboarding where early ideas are tested with participants and design expertise is enacted in specific ways. There are a few studies where these early test activities have been referred to as pilot studies. Interestingly, they all relate to health and wellbeing research (Hielscher, Fisher and Cooper, 2007; Dong and Vivat, 2008; Bossavit and Parsons, 2018; Knutz, Markussen and Thomsen, 2018). This suggests that design researchers are borrowing language from clinical research in an attempt to increase the validity of processes and methods that are unfamiliar to the medical field. This is one example of how the practice-based work of this thesis must acknowledge its precarious positioning between design and health research.

The pilot studies used in this thesis have been developed from a design perspective, rather than the medical perspective that would value qualities of reproduction, validity and efficacy. The purpose of these pilot studies is to make a foray through new and unfamiliar activities to enable behaviours, practices and interactions within moments where patient experience is generated, measured and circulated. The aim of approaching patient experience through these unfamiliar directions is to look at these contexts in new ways and hopefully uncover potentially exciting and unexpected results. This addresses one of the main aims of this thesis: the ways design research creates new ways to think about current problems, what design brings forward, and who or what else design speaks to.

From the perspective of design research, and for the purpose of the research presented in this thesis, the studies are being used as the crucial first practice-based explorations

4 Jerak-Zuiderent (2015) takes a similar approach in social science investigation by slowing down the problem-solution-found plot of accounts in qualitative healthcare interview research.

into working with patient experience to direct further research activities. It is key that the design of the studies are not considered finished design ideas, or even possible or plausible directions for further development or iteration. Instead, they should solely act as props that play a role in enabling interactions to happen (Moggridge, 2007).

In the remainder of this chapter, the three studies are presented in sequence. This is so each study can be described and analysed separately, allowing me to discuss the particularities of each pilot study in the discussion. I explain the background to each of the three pilot studies. Then, I describe the rationale for the study, the results, my reflections and responses. This is followed by an analysis. I am not going to explain everything that happened nor go through each response in detail, but I will highlight key points that developed my thinking on how design can work with patient experience. At the end of the chapter, I weave the pertinent data from each pilot study and my discussion into one paragraph, considering their relation.

Pilot Study 1: Willow Plate

Academic conferences are key sites in which medical and scientific versions of patient experience are enacted, shared and disseminated. For MS research, the ECTRIMS conference is the largest, attended by over 10,000 MS specialists, including neurologists, nurses, health and scientific researchers, and pharmaceutical companies. Often, researchers stand next to their A0 poster (which displays research objectives, methods, techniques, findings and implications), and they respond to questions from fellow conference participants (Figure 22). These academic posters are important tools for research dissemination. As such, I designed the *Willow Plate* pilot study to intervene in the poster session at the 2013 conference and explore the process by which patient experience is translated and produced in this setting.[5]

I approached researchers standing in front of their posters and invited them to participate in the *Willow Plate* pilot study using an information sheet (Figure 23), to which they all agreed. Participants were asked to draw a description of their research on paper, copy this onto a ceramic plate, and then use the plate to describe their research in place of the poster. Traditionally, the existing research visualisation methods found on research posters follow institutional guidelines, have bulleted text, and have computer-generated graphs to represent complex statistical results. However, drawing on a ceramic plate removed these physical and visual constraints, allowing for other representations and forms to come forward. Creating hand-drawn patterns of complex science on ceramic plates was inspired by the elaborate blue and white Willow pattern painted on eighteenth-century

5 To give a sense of scale, there are 4,000 posters on display at ECTRIMS 2013. Recent regulation has stopped pharmaceutical companies taking clinicians to conferences (e.g., paying for their registration, travel, accommodation and meals) if they are not themselves contributing research, hence the large number of poster acceptances (Anand, 2011).

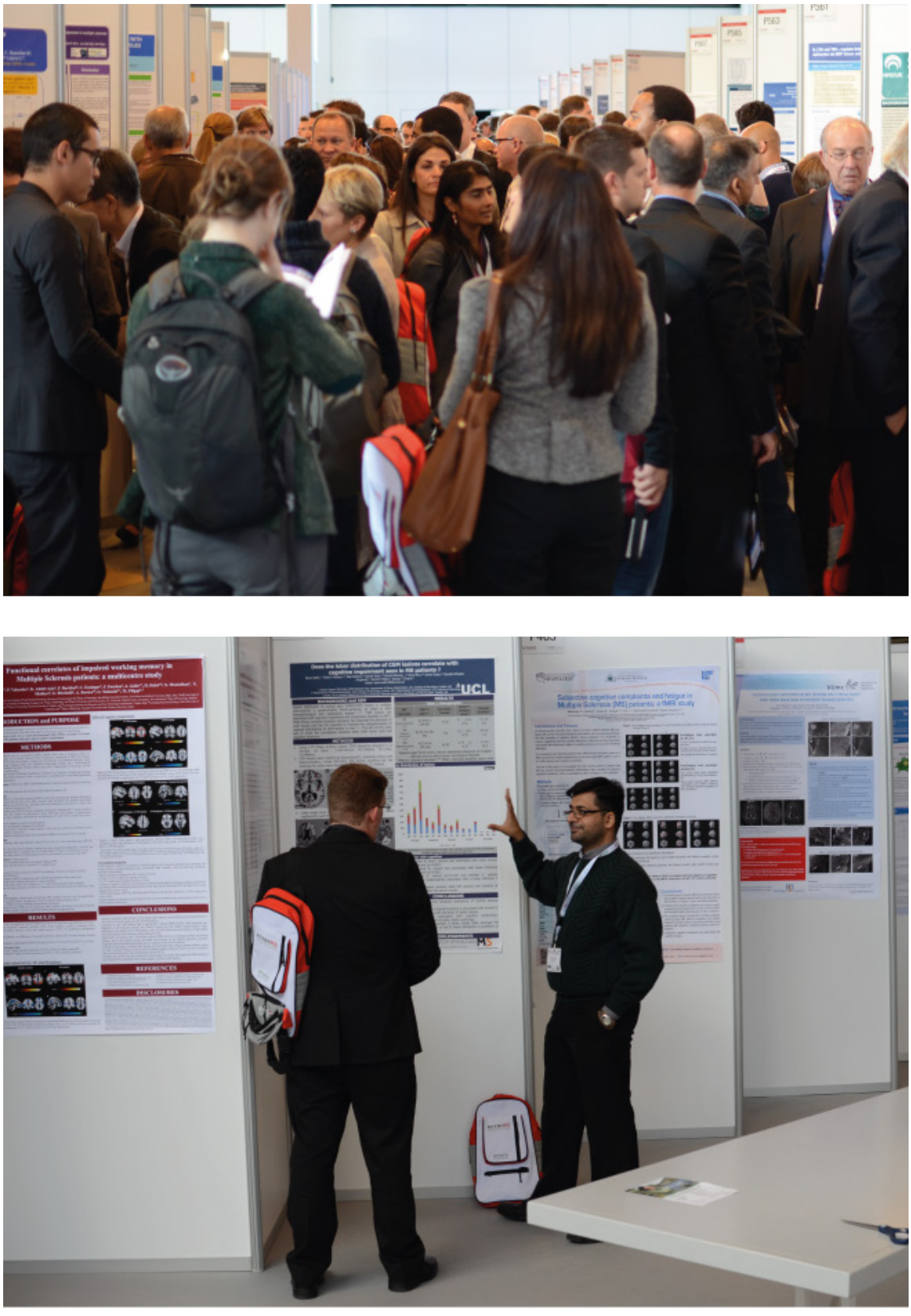


Figure 22 Photographs of the poster exhibition at the ECTRIMS conference, October 2014.

ECTRIMS 2013

Willow plates

The poster session at scientific conferences are an important opportunity for researchers to share their research findings with colleagues.

All posters adhere to a strict format of A0 in size with text illustrating their research methods and outcomes.

For an academic or professional audience, the posters are easy to read and quick to understand but to a lay audience, the posters can be cryptic.

The Willow Plate dates back to 18th century. The plate's unique pattern depicts a romantic fable of two young Japanese lovers as they try to run away to marry.

What is the story of your research?

Could this be communicated through a visual format?

Could you use this, and only this to communicate your research study?

If you would like to take part you will be asked to:

1. Talk through your poster explaining your research. I will film you doing this.

2. Re-interpret your poster by drawing a story on a white ceramic plate using a blue pen.

3. Talk through your diagram describing your research.

I hope to collect 20 plates from the ECTRIMS conference between the 2nd and 5th October 2013.

I am currently a Research Designer at Queen Mary, University of London working with Professor Giovannoni and Professor Baker.

This project is part of my PHD in the Design where I am using design research to explore the multiple realities of multiple sclerosis.

Professor David Bakers willow plate

Figure 23 Instructions given to participants to explain the Willow Plate exercise.

tableware conveying Chinese narratives and fables. I drew similarities between how an observer must learn to understand these distinctive patterns for the story to unfold as being similar to the technical presentation of research on a scientific poster and the technical knowledge needed to be able to understand the poster content.

Engaging researchers to hand draw a description of their research created an opportunity for them to be spontaneous and expressive, much like *Surrealist Games* (Brotchie and Gooding, 1995).[6] The aim of this was to help bring about surprising or non-ordered responses from participants, breaking their traditional thought patterns to create unpredictable outcomes.

Eight participants (with roles as biomedical researchers, PhD students, pharmaceutical representatives and clinical academic researchers) engaged in the activity with even more conference delegates interacting with these participants throughout the process shown in Figure 24-27 (Gurkan et al., 2013; Kearney et al., 2013; Sethi et al., 2013; White et al., 2013).[7] Below, I report on three examples of unexpected encounters from the activity:

1. In the poster hall, there was a steward's station that provides support for poster authors to hang their posters. I stored the plates here during the activity, and as I returned with each completed plate, one of the stewards became increasingly interested in the activity. On the creation of the final plate, the steward left the station to approach the researcher, listened to the description of the plate, and then asked questions about his sister (who was a participant of a cancer research study).

2. While one of the PhD student participants was drawing their plate, a conference delegate asked what they were doing. They responded with 'We're making our work easy for patients to understand'.

3. One week after the conference, I received an email from the participant who worked for a pharmaceutical company and created Plate 2 asking for images of the plate so they could request legal approval for it. All material produced by pharmaceutical

6 I filmed the participants explaining the research on their poster, drawing their pattern on paper and then on the plate, and using their plate to explain their research again. At the end of the activity, I took a portrait photograph of each participant with their completed plate.

7 I had originally aimed to work with 20 researchers, but the participants took longer than expected to draw and re-draw their plates, so I reduced my expectations of this number and was able to produce eight completed plates.

Figure 24 Photographs documenting the creation of Plate 1, entitled: *Does the lobar distribution of cortical grey matter lesions correlate with cognitive impairment seen in multiple sclerosis patients?* The first author, Varun Sethi, is pictured above.

Figure 25 Photographs documenting the creation of Plate 2, entitled: *Immunogenicity with peginterferon beta-1a in patients with relapsing-remitting multiple sclerosis: data from the pivotal phase 3 ADVANCE study.* The first author, Joleen White, is pictured above.

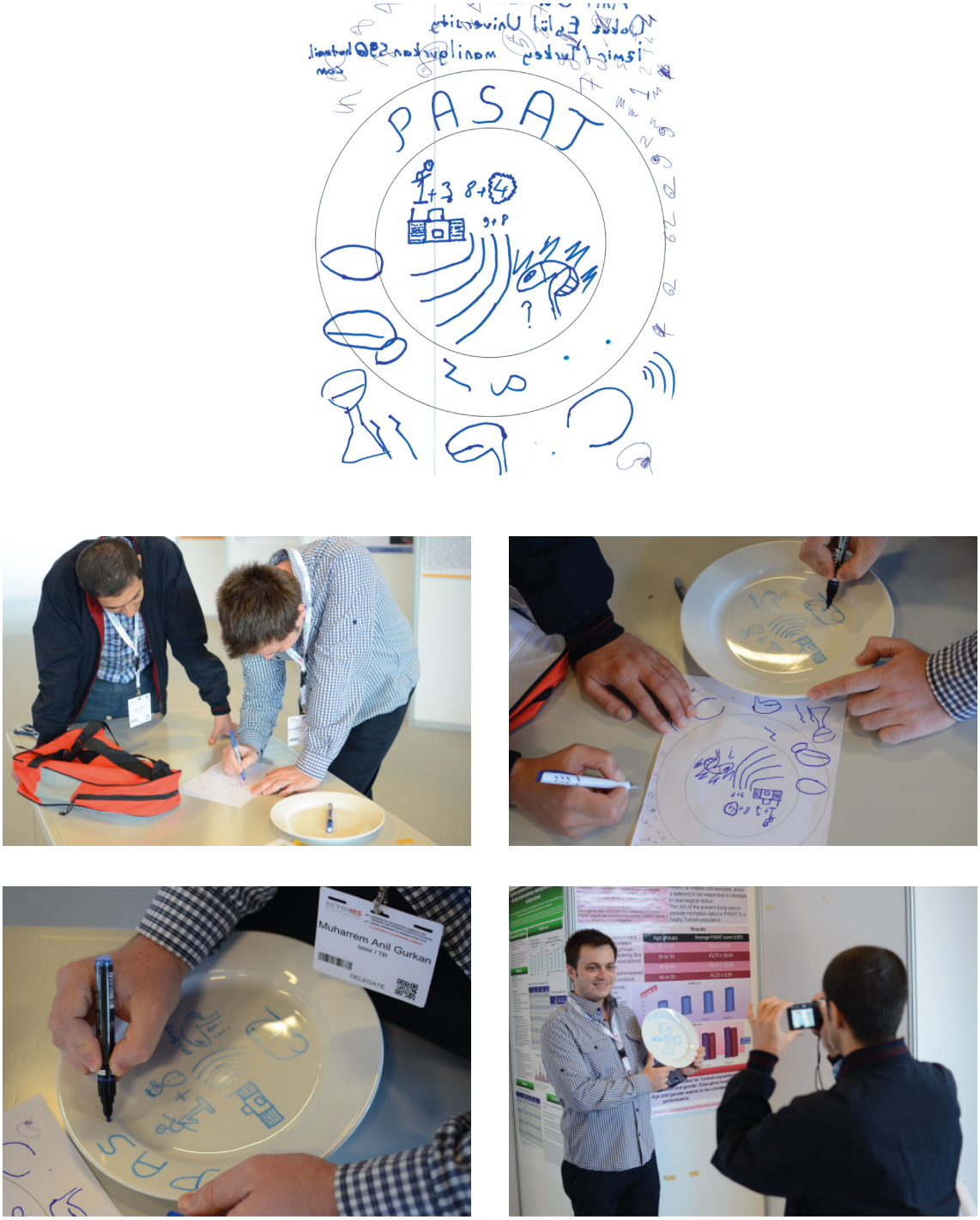


Figure 26 Photographs documenting the creation of Plate 3, entitled: *Paced auditory serial addition test: normative data in a Turkish population*. The first author, Muharrem Gurkan, is pictured above.

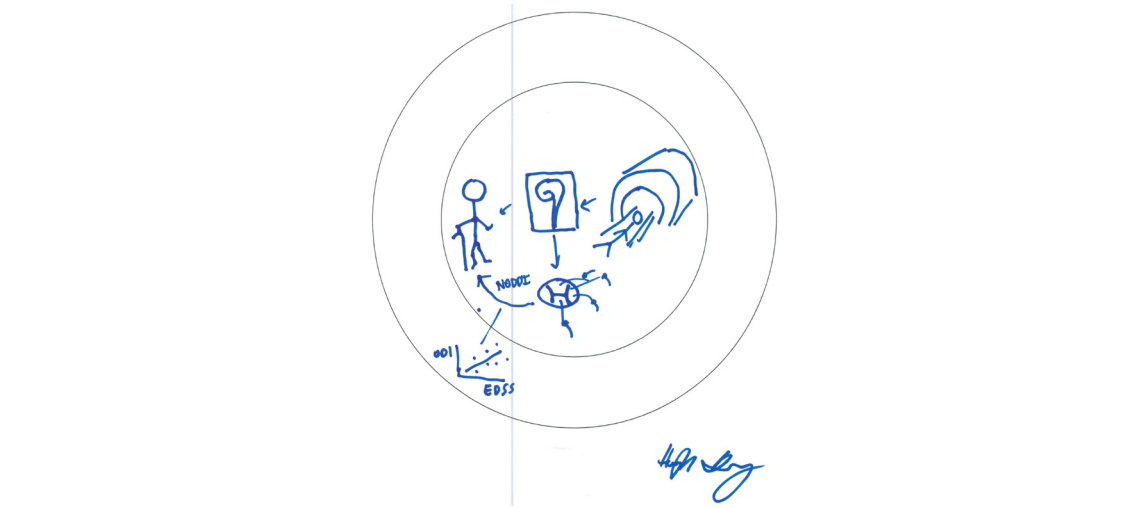


Figure 27 Photographs documenting the creation of Plate 4, entitled: *Neurite orientation dispersion and density imaging in multiple sclerosis spinal cord.* The first author, Hugh Kearney, is pictured above.

companies need to comply with the Association of the British Pharmaceutical Industry guidelines (PMCPA, 2016).

The activity was met with positive responses from the participants who engaged with the study and from passing conference delegates commenting 'what are you doing?', 'Wow - interesting' and 'this is better than your poster'.[8] This could be due, in part, to many things – such as the novelty of the activity, its similarities to public engagement projects that are common at UK research institutions, or my association with patient-involvement sessions that I run at ECTRIMS.

I was surprised that none of the participants re-drew any of the scientific visualisations, line graphs or illustrations from their original posters. Instead, they drew a variety of objects and icons, such as a patient lying in an MRI machine, brains being cut, MRI scans of spinal cords, an ear, music notes, a house, a bonfire, a bicycle, a money symbol, male and female bodies, walking sticks, and happy and sad faces. These objects provided insight into some of the other bodies, medical apparatuses and techniques necessary to conduct their work that are not included or represented on the original poster. This suggests the pilot studies can intervene in the chain of translations that produce patient experience, involving other experience phenomena, i.e., stewards, conversations, graphs, and approvals.[9]

Dealing with the mess

Academic posters as technologies of experience produce cleaned-up versions of **Experience 2**, which are precisely framed as workable, generalizable, knowable, analysable and measurable as immutable mobiles, like other forms of objective data (Lynch, 1985, p. 43).[10] When immutable mobiles that have to travel around and get worked upon are made in this clinical research setting, things get left out. The creation of the plates slowed down this translation and inscription process. It also enabled me to pay attention to the removal of objects or cleaning up of the mess of unworthy objects. This included the brains of deceased patients, dissected spinal cords, medical apparatuses, and emotion, in addition to tensions and complexities that were screened out and erased (Star, 1983), ultimately resulting in new versions of cleaned-up research. Moving away from cleaned-up versions exposes different realities of this work, including failed studies, patients' feelings, emotions and gender, which

8 The plates were not intended to be used beyond the poster session because I was specifically interested in the process of their creation, rather than them as a final product or resource, thus in part reflecting the short lifespan of the posters themselves. Many posters are not claimed at the end of the session and are disposed of after the poster sessions by the stewards.

9 By this term, I refer to objects, responses, and events caused or performed by doing patient experience.

10 Latour and Woolgar (1986) refer to this as the work that goes into the social construction of scientific realities through the making of 'facts'.

play an important part in influencing research, and which are left out by medical science.[11] By looking closely, I analyse the negotiations between included and excluded visualisations, bodies and tools and create opportunities to arouse 'a different awareness of the problems and situations that mobilises us', and the scientific community (Stengers, 2005, p. 994). Slowing down brings this new awareness to the problems and situations that are not predetermined or vetted through the translation process. This pilot study shows that having a different activity represent research brings into play research elements that would have otherwise been stripped away.

This brings me to an important question: how do technologies of experience generate versions of experience with issues implicit within them? There is a possibility for a less predictable or prescribed version of experience to come forward if you do not adhere to the rules and traditions of medical science. This version is less scientific, as it is not beholden to characteristics of heterogeneity, comparability and transferability. Instead, it is more about context and specifics, which result in a different form of knowledge claim. This begs the question, should experience be solely based on clean accounts? Or, instead, what happens when we follow Stengers and reclaim the mess, learning how to deal with what escapes objective categories (2002, p. 27)? Then, technologies of experience must be designed to allow for problems and issues to come forward.

Misbehaviour

Stengers argues that an understanding of slow science must include the ways that other kinds of experience come to matter for other collectives, suggesting a diversity of actors involved in patient experience (2002, p. 84). Translating a paper poster into a ceramic, hand-drawn plate mobilised experience in a new and unusual format and enabled new connections amongst different implicated actors to come forward (Stengers, 2002, p. 252). This included the unexpected actions and responses from the steward sharing a healthcare experience of a sibling, the pharmaceutical industry seeking regulatory permissions, and the PhD student's assumptions becoming explicit. In the form of a plate, experience comes to matter (or not) for the implicated actors.

In the conference setting, researchers, scientists and clinicians are seen as more powerful than non-experts. Additionally, in this setting, the technologies of experience ascribe, or script, the roles of researchers, stewards and representatives, making them experts participating in a research dissemination activity with other experts. This is evidenced with the PhD student's response exposing a knowledge hierarchy between the authoritative position of researchers and others. Here, design explores this directionality of

11 MS is predominantly a disease that affects women, yet most people recruited onto studies are men, and there is very little research into issues that affect women (pregnancy, menopause, etc.). This, coupled with the uneven gender distribution in the clinical and academic workforce (most MS specialist clinicians are male, and almost all MS nurses are female) is gaining more attention (International Women in MS, 2018).

knowledge and expertise and shows how the involvement of different formats exposes this. The plate becomes an accountable version of experience for the steward, encouraging him to misbehave as a steward (Michael, 2012), which allows him to become a resource in his interaction with the expert. This re-configures his identity as a brother an associated patient experience. The steward takes the plate seriously, has the powerful right to do so, and in doing this, serves to trouble the very exercise of the poster when he does not value or feel entitled to participate in the workable, generalisable and knowable **Experience 2**. But, to treat audiences symmetrically, I cannot say the poster is more important, serious or sensible than the plate or steward's stories about his sister. The methods of the pilot studies deliberately leave the definition of the actors underdetermined and the direction of travel open. Here, I have learned that patient experience can travel in different directions and also be reclaimed.

In the process of exploring other ways of eliciting experience through design research, it is important to be aware that the techniques are still beholden to certain requirements, such as regulatory guidelines of the pharmaceutical industry and organisational rules and regulations. If thought about as a technology, they predetermine the identity and role of the actors in the script, formatting the conduct of researchers and of where and how they can circulate. Although, in the example of requiring company approval for the plate, the experience phenomena is able to undermine these pre-existing identities, roles and scripts by becoming subject to the demands of medical science and highlighting them as unnatural. It seems ridiculous that the same requirements for scientific posters are applied to the plate, a very different technology of experience that exposes different things and acts radically different, which the company's rules evidently consider equivalent. This builds on previous questions around whose interests are these versions of experience produced and what counts as experience, and for whom.

Pilot Study 2: How far can you walk?

The second pilot study explores how medical versions of patient experience and patients walking distance are defined and generated through outcome measures. Interestingly, there is lack of consensus within the neurology literature and clinical field around exactly how to measure and record the optimum walking distance of a person with MS safely and rigorously within clinical research and practice. The following approaches and associated critiques are put forward: a clinician pushing a trundle wheel while walking with a patient is criticised to be time consuming (Bethoux and Bennett, 2011)(Figure 28); patients walking on a treadmill is said to be unrealistic (Bethoux and Bennett, 2011); and patients verbally describing their walking ability over specific distances, or between two landmarks such as the hospital and the tube station, is flawed because people are unable to judge exact distances (Sharrack and Hughes, 1997; Giantomaso et al., 2003; Commins et al., 2013). Arguably, this debate is preoccupied with determining the optimum environmental conditions and practices to generate clinical data through simulating walking in *real life*,

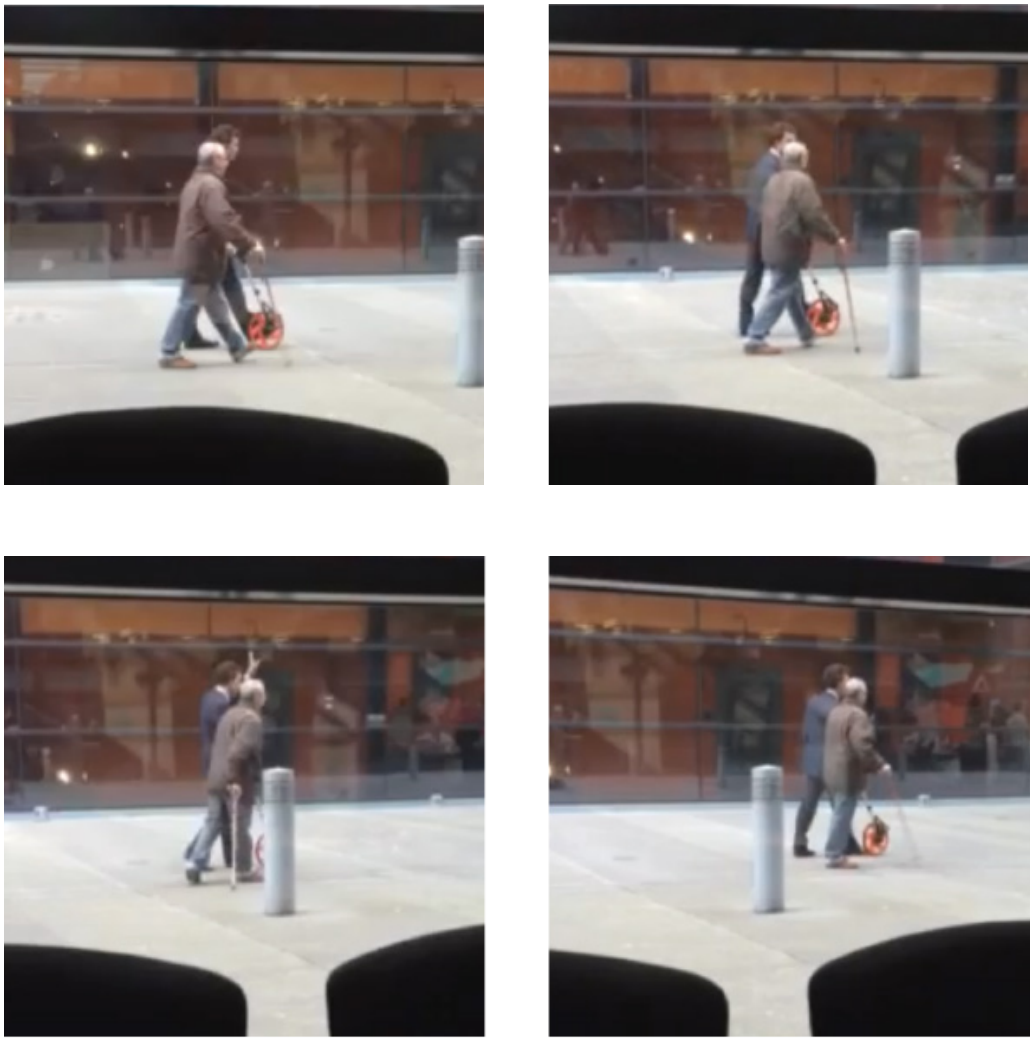


Figure 28 Stills from a video recorded on my phone of a patient with MS using a walking stick and having their walking ability measured by a neurologist outside the Blizard Institute in Whitechapel. I have observed my clinical colleagues 'walking' a patient with MS on many occasions. In doing this, they adhere to the requirements to generate walking distance for a clinical trial.

i.e., re-creating a patient walking that is not for measurement purposes. This argument is based on this field's understanding and associated assumptions of thinking about **patient experience 1**. I am interested in how this procedural uncertainty from within the neurology field reflects their conceptual assumptions about how patient experience is generated and performed and how this materializes in the practices in conducting measurement activities with patients.

In the *How far can you walk?* pilot study, the participant, who is a consultant neurologist (not a person with MS), was instructed to walk 360 meters before pausing for a two-minute rest. After the pause, we continued to walk for 360 meters, then paused again, and so on until we reached the final destination. The distance of 360 meters was selected because this was the distance that the person with MS filmed in Figure 28 could complete before needing to rest. I measured the distance by pushing a trundle wheel and documented the activity with a sound recorder, video camera and the Moves application running on my phone (Figure 29-31).

The pilot study aimed to explore the assumptions of simulating patient experience as a measurement activity. For this design intervention, I drew on approaches from user studies in design, where the subjective experience of users are simulated as part of the design process to create a 'connection with the users' and get close to 'contexts, actions, feelings, attitudes and expectations' (Mattlemäki, 2002, p. 267) through empathy probes and experience prototypes (Buchenau and Suri, 2000) by simulating the measurement activities, tools and behaviours.

This was conducted in the neurologist's everyday life setting of commuting to work. This was done to see if it could provide active participation in another's subjective experience, as these tools claim it can (Buchenau and Suri, 2000; Mattlemäki, 2002). Also, it aimed to explore the apparent need to provide ways to help physicians gain empathy for their patients, which is well known in medicine (Halpern, 2003; Jeffrey, 2016).

On the morning of the study, the neurologist and I walk from their home in South West London at 7 am to the tube station, stopping every 360 meters. While we walk and pause, conversations cover multiple topics (e.g., our immediate surroundings, topics the participant brings up of their next house move, people who live in the area we are walking through). By the time we arrived at the station it was later than usual. As such, rush hour made it impossible for us to board the train. The participant suggested we travel south one station to board the train when it is quieter, before it gets to this station. We do this and complete the journey to their work. The consequences of conducting this activity and deploying this data on the participant's commute to work was immediately apparent for that participant.

Not surprisingly, while walking our conversations started around the task at hand and the limitations of only being able to walk 360 meters. It then moved on to topics of interest to both of us, such as living in London, house prices in the area, marathon training, and

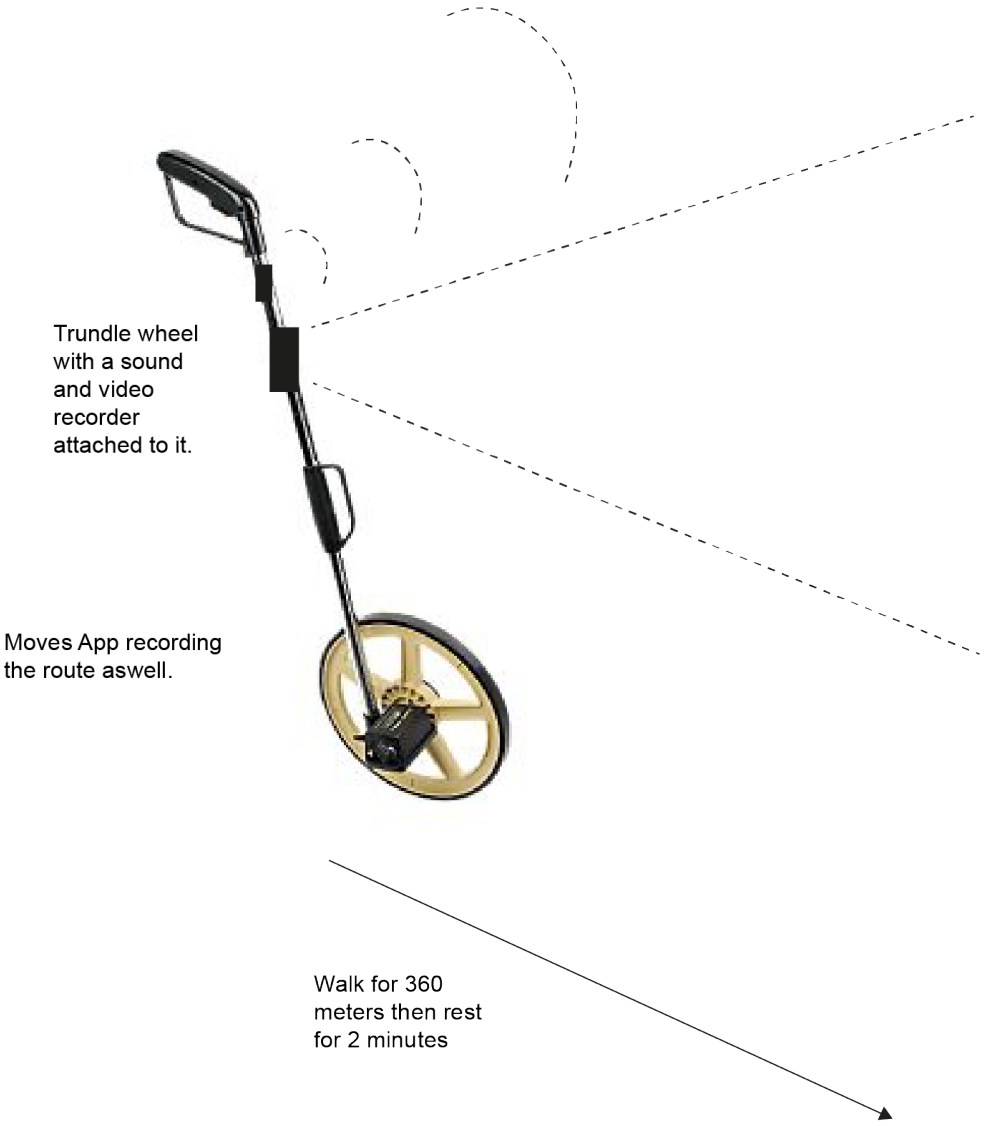


Figure 29 An illustration of the set-up of the walking device and different technologies involved in recording the pilot study.

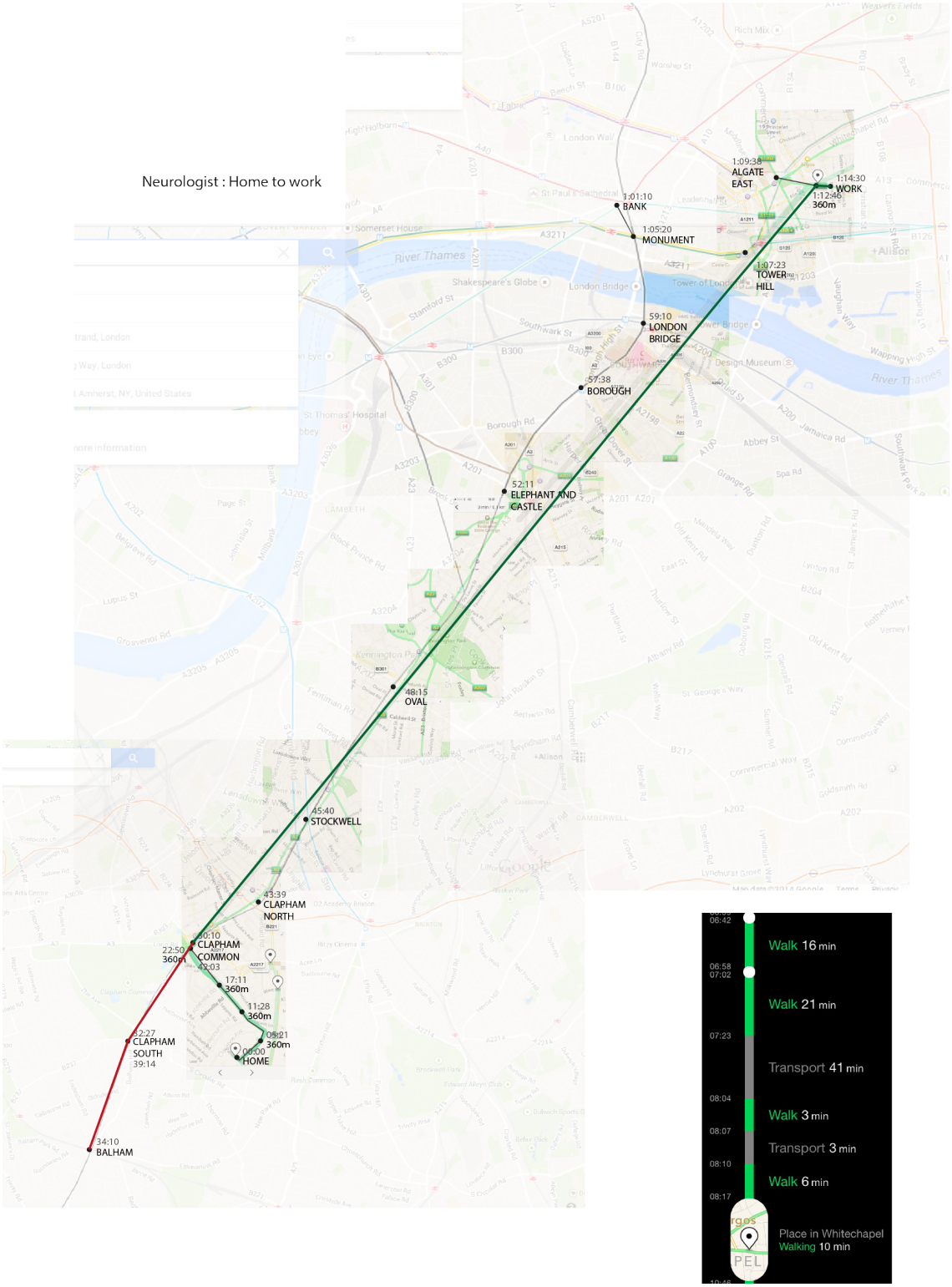


Figure 30 A compiled illustration of the tracking data gathered from the Moves App running on my phone showing the distance covered and time duration. By visualising this data, I am able to show our journey and the misdirection of the train, shown in red. This shows the route that we travelled from SW7 to E1 plotted on a map, marking each time we completed 360m in distance with a time stamp from the sound recording. We travelled to the underground station, then passed through it. The total journey took 1 hour 14 minutes.

Figure 31 Video stills taken from the camera attached to the trundle wheel show clips from the journey on the way from the underground station to the participants work.

a recent public scandal of someone who lives in the area. What we did not consider were the implications of only being able to walk 360 meters at a time for a person with MS or the associated activities related to this, such as having to leave at a different time to incorporate the rest times, pre-planning areas to rest, and asking for a seat on a busy tube. These are all important considerations that people with MS who have limited walking ability must consider, and will be crucial to ensure they can complete the journey.

When conducting this activity and simulating the walking limitations as an embodied feminist researcher, I realised the limited access I had to any actual pre-existing walking distance limit and also any pre-existing patient experience. The participant actually became frustrated by the activity and continually having to pause. After the activity, I attempted to visualise, illustrate and capture some of the other things that came forward on the walk and created a visual account of the study. This made me reflect on the constraints I had designed into the activity, and I compared them to the constraints in place within the medical simulations with patients – tools, routes, clinical observation, time of appointments, etc. – which impact its creation.

Practices of simulation

Measurement activities, such as walking a person with MS, attempt to uncover, measure and record the true experience of another person through practices of simulation. In temporarily signing up to this claim, this pilot study aimed to remove the true walking distance from the patient body and sought to apply it in a different event to explore how it would travel. The pilot study shows how the artificially imposed walking limitation of 360 meters (of a person with MS on a person that does not have MS) is only one part of a person with MS's experience, as it was also only one part of the stuff that happened on our walk. This demonstrated the entangled relation of both humans (patients, clinicians and researchers) and non-humans (measurement tools, recording devices and trains) in the ongoing practice of making experience, and shows how the simulations themselves actually create new **Experience 3**, which are dependent on the measurement tools, bodies and subjects that produce it. Therefore, if a true distance existed, it could never be separated from the other potential things going on (e.g., the weather, possibly having a relapse, possibly having a bladder infection, and their shoes).

Measurement outcomes as technologies of experience, attempt to capture a snapshot of a person's life in the production of stable, valid and generisable measurement. But as a practice of simulation, they are perspective-less assessments, much like disembodied scientific objective knowledge (Haraway, 1988), which removes standpoints of patients and researchers from nowhere (Mol, 1999). Feminist scholars point out that walking is an embodied practice (e.g., [Haraway, 1988]). Disembodying data may make them transportable to certain places within medical practice and scientific research (audit reports, medical notes, cost calculations), but it does not transport it to other bodies. Scientific reliability and

robustness is situated, bound to the constraints of its production. So when these leave, they leave behind specific reliability and robustness (Stengers, 2005, p. 118). So walking with a person with MS works in a very constrained, narrow way that is utterly unlike 'walking' in an everyday context. For it to be successful, it depends on the conditions of its creation.

This pilot study shows the tension of how measurement outcomes value impairments, such as walking, and shows the tension of how standards are set up and fail to shift during the course of an illness. This raises important questions about how experience is represented in knowledge practices and how crucial things such as endpoints of improvement or deterioration are determined. The consequences of this is seen in how population metrics are applied in the PIP as 'senseless criteria'. These technologies produce or exclude subjectivities with immediate material affects that detrimentally impact people's lives. By slowing down this technology, I reject the properties of fast science and what it represents – efficiency, replicability, reliability – and discover these relations have been replaced by oppositions between contradictory interests (Stengers, 2005, p. 103). Examples of contradictory interests that came forward in this intervention were that of deciding the best tube stop to get on at, consider the time of day to complete an activity, and figuring out how to cope in extreme weather.

The pilot study shows how these representations of reality through technologies of experience as different words, images and practices are contestable when taken out of the clinical field. Although I attempted to use design visualisations to explore other representations, it seems clear now that the way to move forward would be to ask how patients might represent themselves. This contributes to my understanding of experience, as it highlights that **Experience 2**'s quality of transferability is actually an assumption. In other words, as an immutable mobile, the version of experience in this pilot study does not move or transport anywhere else as it is presumed to.

In summary, the contribution of this pilot study was to show that you cannot actually recreate other people's experiences, as these are embedded in specific contexts involving specific objects such as environments and patient bodies. This study also showed that as the participants of the study discussed other things while walking, so will a patient when being measured. Patients have other concerns, and walking can only be part of it. This study also contributed that simulation can only teach you about part of what is going on in the experience of a measurement activity. There are larger things happening that you do not have access to through this method. This is particularly important for designers to understand when working with patient participants so they understand that disability, for example, is thoroughly intertwined with other aspects of a person's experience that they will not get access to.

Pilot Study 3: Consultation pie

At the Royal London Hospital, people with MS have appointments with their clinical team in either MS-specific or neurology clinics held in the outpatient department (Figure 32).[12] The clinic always has a busy waiting room with patients waiting to be seen, family members accompanying patients, healthcare assistants moving notes, and medical students approaching patients to take part in research, audits and database projects.[13] Data generated from patients through these tools go on to create data versions of patient experience (**Experience 2**) circulating as academic papers, audit reports, research posters and databases.

The *Consultation Pie* pilot study is designed to explore how patients and healthcare staff report on actual events once probed by a recording tool in order to question what these tools gather, what they presume to be valid data (**Experience 2**), and what is left out. The pilot study activity consisted of me giving both a healthcare professional and a patient a recording tool (much like an over-photocopied A4 paper questionnaire) before and after the consultation, shown in Figure 33 and Figure 34. Both groups were asked to describe how they thought the time would be spent in the consultation on the first sheet. It then asked how it was actually spent on the second sheet, completing a section of the pie for each activity.[14] So, for example, 100% of the pie would represent the entire clinic time, and they could draw different percentages of time for each activity or topic.

The tool was designed to prompt participants to respond and capture these responses in an open way. Arguably, measurement tools with pre-determined responses work to maintain the assumptions that the tool itself is a rational actor and that there is a logical relationship between the question being asked, its intentions and the format for recording the response. Further, that data generated from the tool can then be used elsewhere, unbeknown to original context, and keep its (human) logic. This tool puts this assumption under pressure by blurring the boundaries of what it is intended to do. I am interested in opening up the assumptions within measurement tools to consider how to question their intention.

I attended the MS clinic on two occasions and I approached five patients who all agreed to take part. Once the patient had verbally agreed to participate, I informed their healthcare professional (two patients saw the neurologist, two saw the MS nurse and one saw

12 Regular appointments are allocated fifteen minutes, but patients who are newly diagnosed will be given an appointment slot lasting thirty minutes. However, most run over that time. Depending on their health and which treatment they are on, patients could attend this clinic three times a year or once a year.

13 The Royal London Hospital is a teaching hospital and is linked to the medical school at QMUL – Barts and The London School of Medicine and Dentistry. Trainee doctors of different levels (medical students, foundation year doctors, registrars) are frequently involved in this clinic when they are on placement with the Barts MS team. Depending on their role, they can sit in and observe clinics, conduct research in the waiting room or run consultations for the clinicians.

14 The concept of patient experience is problematic because researching 'patient experience' would ignore the assumptions of the performativity of speech acts and the views of patients reporting; therefore, this pilot study is described as recording humans' expectations rather than their experiences. Further, I had doubts when I found out others had written about how patients learn to enact the types of experiences that are legitimate (Renedo and Marston, 2011). In other words, I wanted to avoid asking people about their experiences and them providing a predictable response as this would play into the assumptions that I have previously criticised earlier in the thesis.

Figure 32 Photographs of the Royal London Hospital Outpatient Department consultation and waiting room in Whitechapel, where the MS clinic takes place.

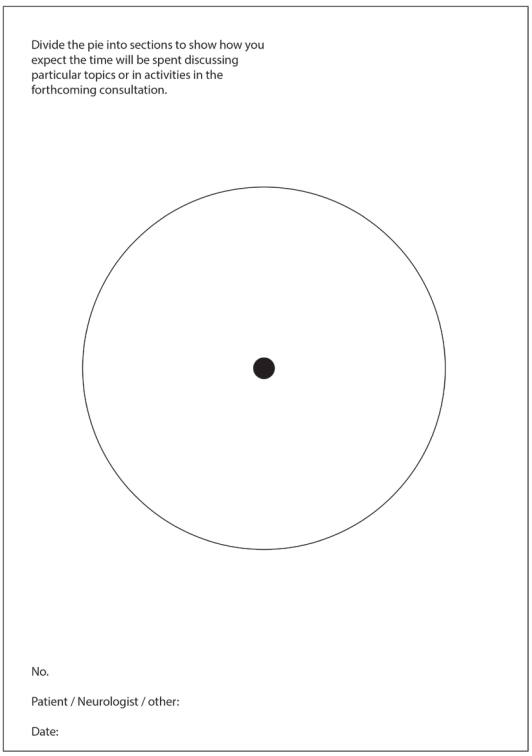


Figure 33 Copy of the blank pie given to each participant before the consultation.

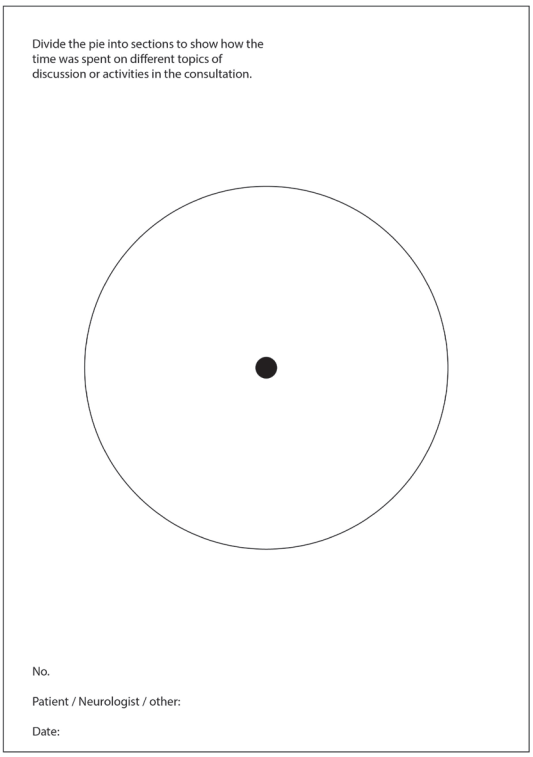


Figure 34 Copy of the blank pie given to each participant after the consultation.

the registrar) and asked them to complete the pie for that patient noting their expectations of how the consultation would go. Figure 35-39 show scans of the completed consultation pies.

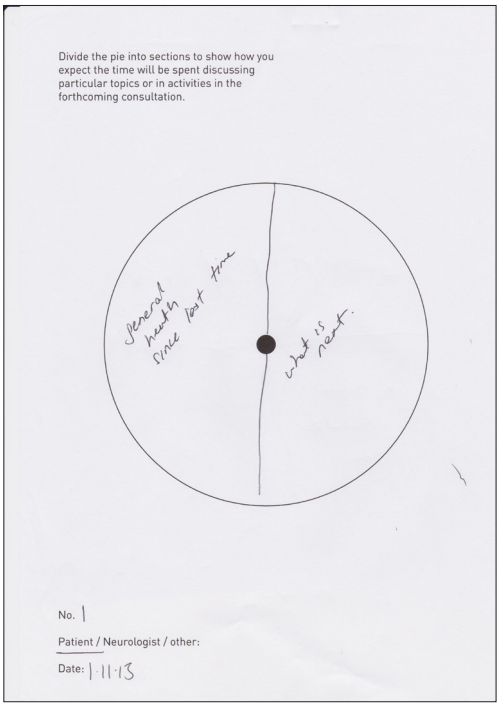
There are a number of typical topics that are covered in a neurology consultation, 'small talk/catch up', 'recent events/new symptoms', 'old symptoms', 'social issues', 'future therapies', 'medication review', and 'blood tests', which were described to me in a preliminary activity with the neurology professor. Yet, for patient 2, the neurologist includes 'olive oil' as a before and after entry. This is because this patient always brings the neurologist a bottle of olive oil from her home in Spain. This is clearly an important object involved in their time spent together, yet it would certainly not be something that would be valid in a database, nor in medical notes.

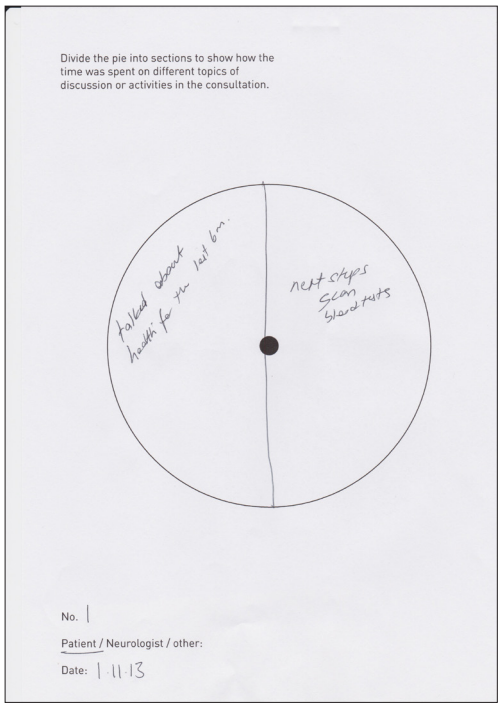
Involving different healthcare professionals in the study allowed me to observe how they responded to the tool differently, and the scans show visible differences in the amount of information from the neurologist (Patient 1 and 2), the MS nurse (Patient 3 and 4) and the registrar (Patient 5).

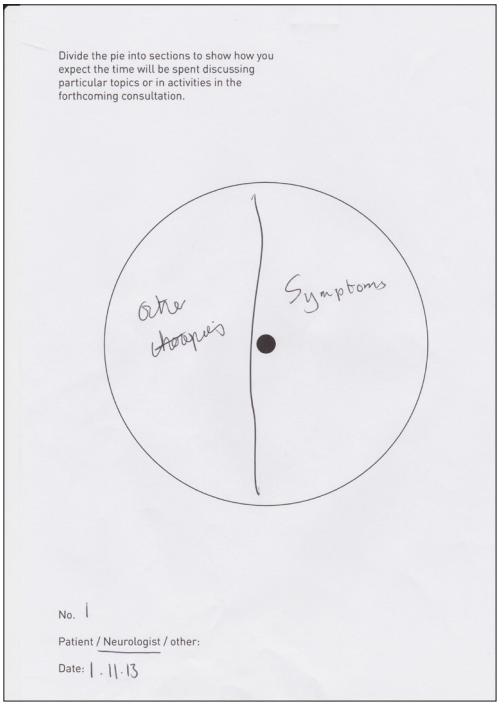
The physical paper object worked well as a tool to facilitate interactions between myself and the participants without having to verbalise their response (**Experience 1**). Not affording, or scripting (Akrich, 1992), specific actions such as ticking boxes or selecting from pre-determined responses enabled other responses to come forward . The activity generated a variety of responses in participant reactions to the activity and content in what it gathered because it was an unusual task for people to be invited to complete.

Working together with other experience phenomena

The ambiguity and openness of the tool leaves space for other phenomena, with different types of agency, to come forward in this activity. The olive oil bottle is a non-medical object that the neurologist and the patient have made an accountable object of patient experience and validated it by including it in the tool 'before' the consultation, the patient bringing the bottle, and then repeating this entry in the 'after' pie. This situated interaction suggests that they have established a way of working together, with a different type of experience phenomena involved in patient experience allowing one concept of what is important (discussions on symptoms and treatments) to move aside for another (receiving a bottle of olive oil as a gesture). It mobilises another kind of knowledge, through a situated activity of knowing, drawing attention to which objects are counted as valid in medicine and which are not. Stengers (2005) points out that what matters is rather the possibility of creating relevant modes of togetherness between practices, both scientific and non-scientific, finding relevant ways of thinking together. This is especially the case for the neurologist who has developed professional autonomy (Winthereik, van der Ploeg and Berg, 2007). This version of patient experience is based on their mutual dependencies and ambiguities, as well as the ambivalences of the doctor-patient relationship. However, this is screened out of







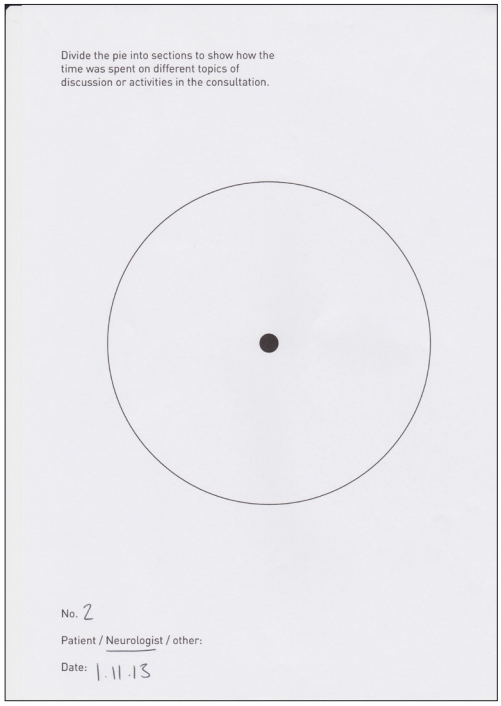


Figure 35 Four scans of the pies completed by Patient 1 and the neurologist for the consultation pie activity.

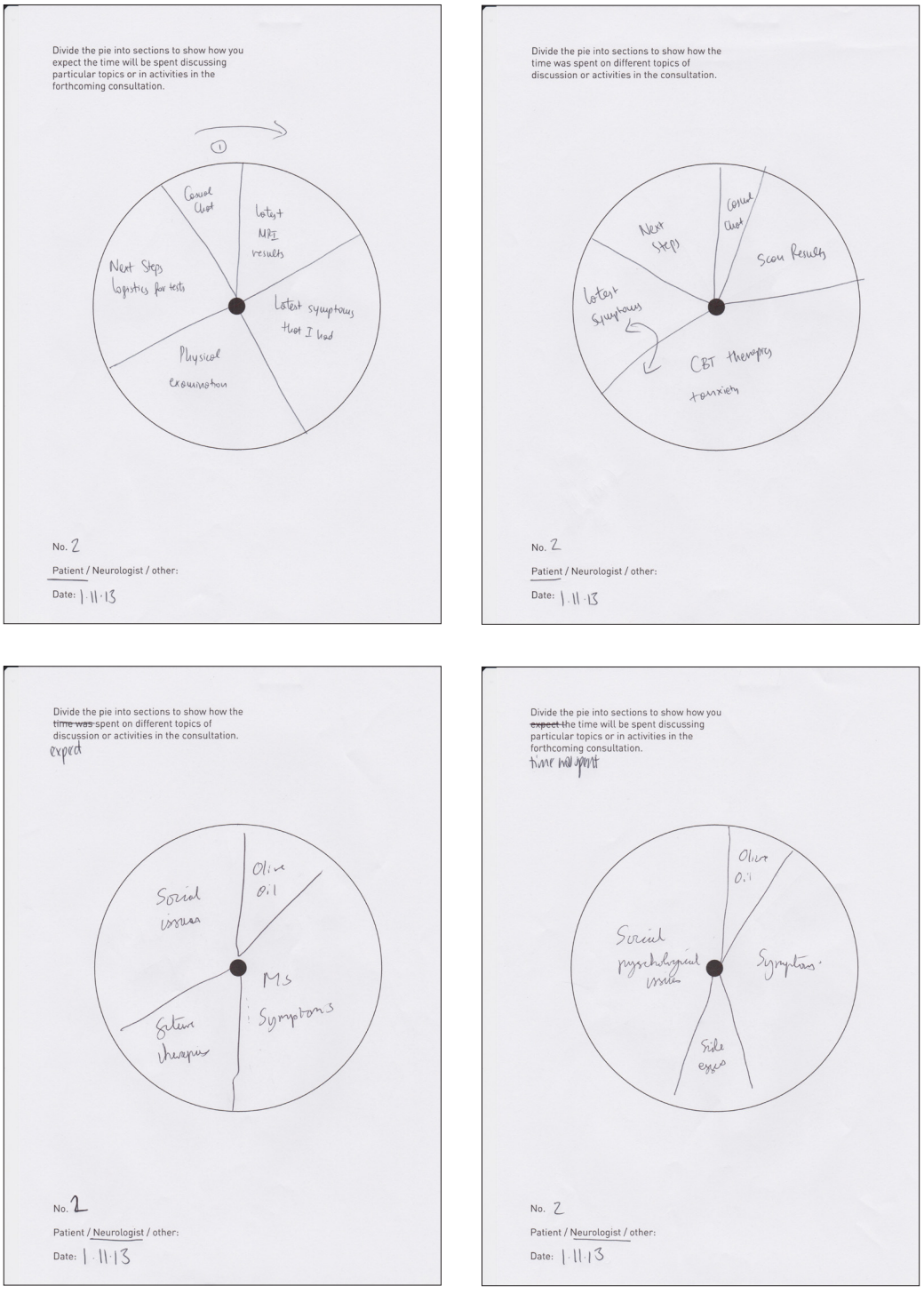


Figure 36 Four scans of the pies completed by Patient 2 and the neurologist for the consultation pie activity.

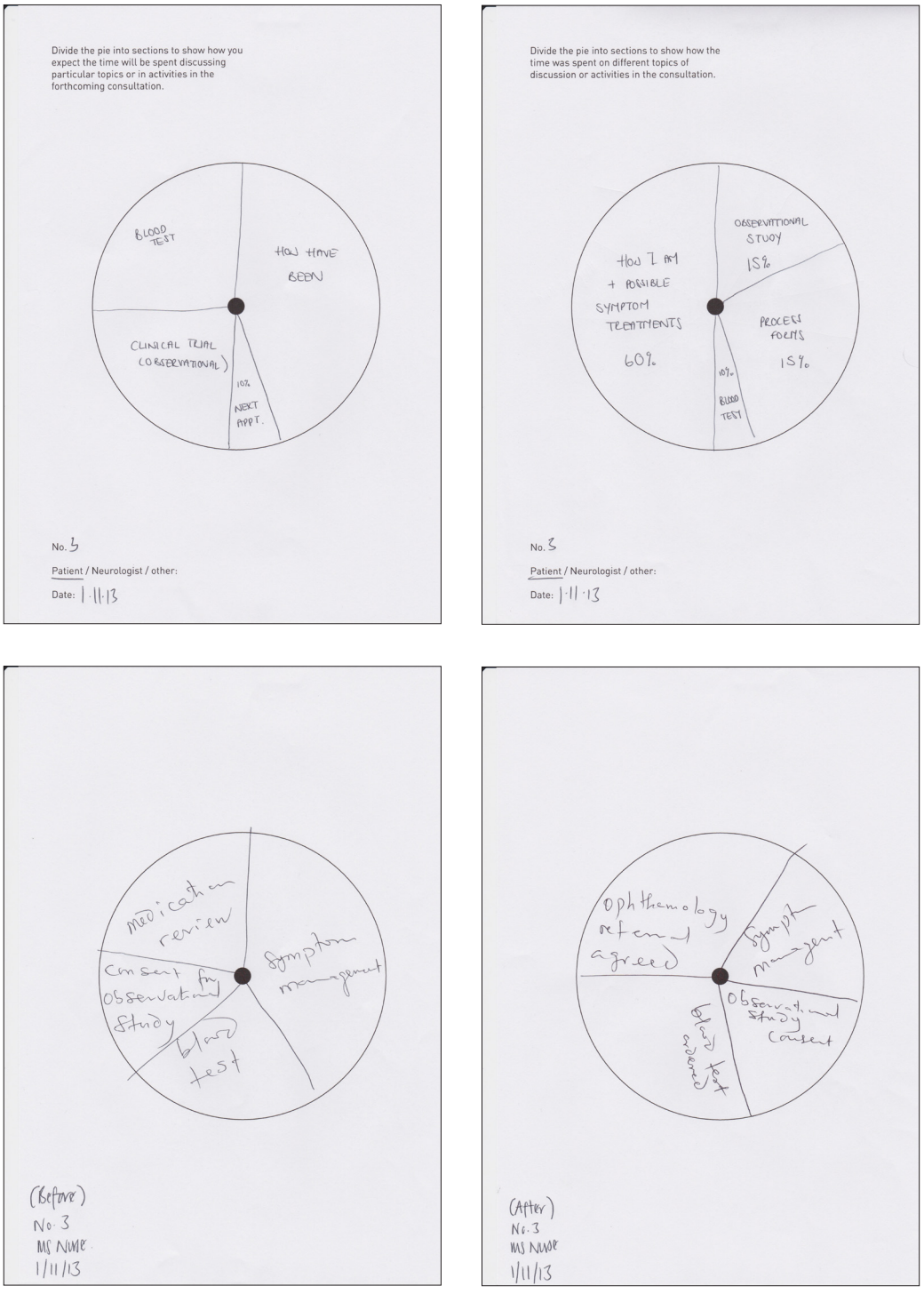


Figure 37 Four scans of the completed pies by Patient 3 and the MS nurse for the consultation pie activity.

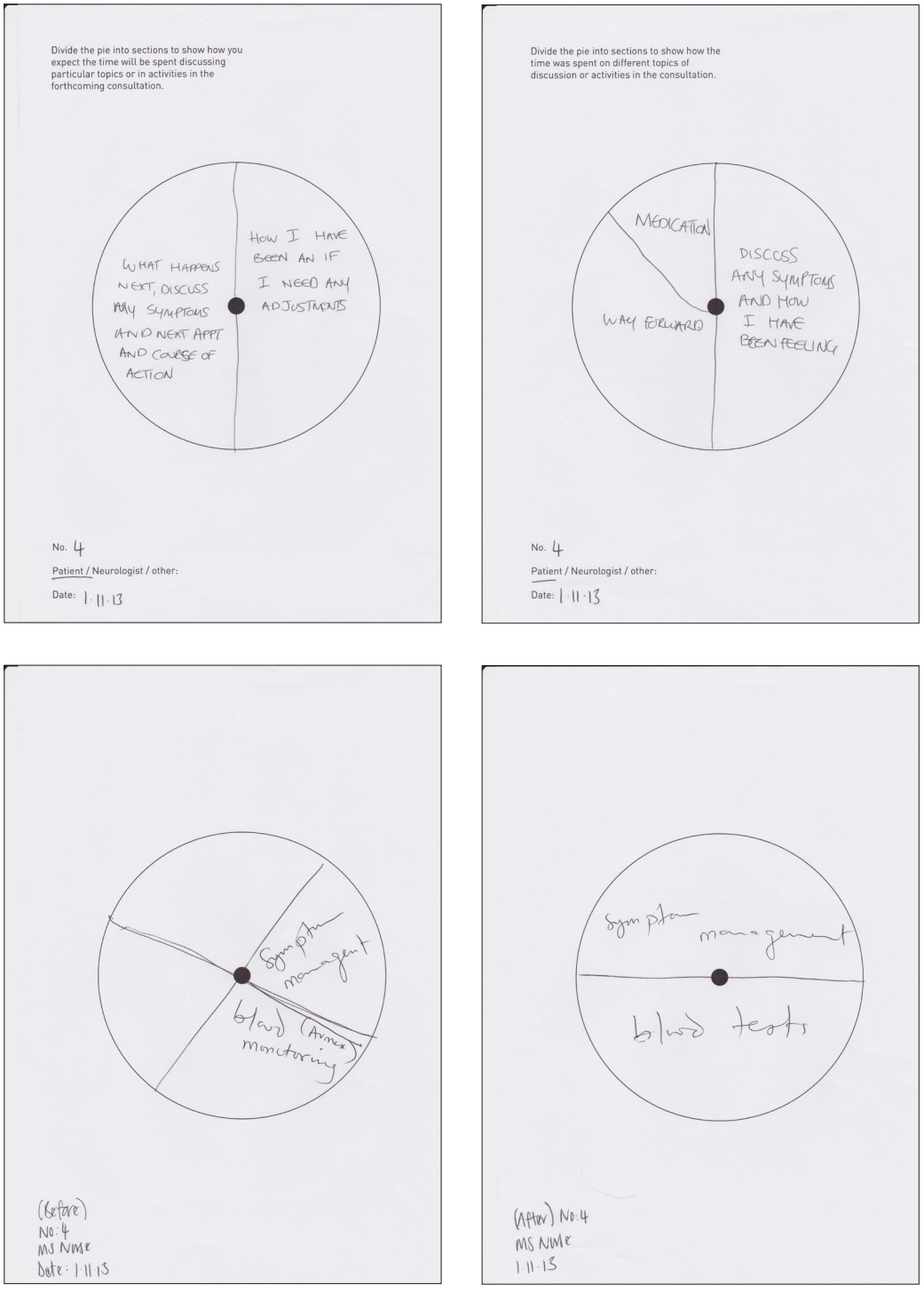


Figure 38 Four scans of the pies completed by Patient 4 and the MS nurse for the consultation pie activity.

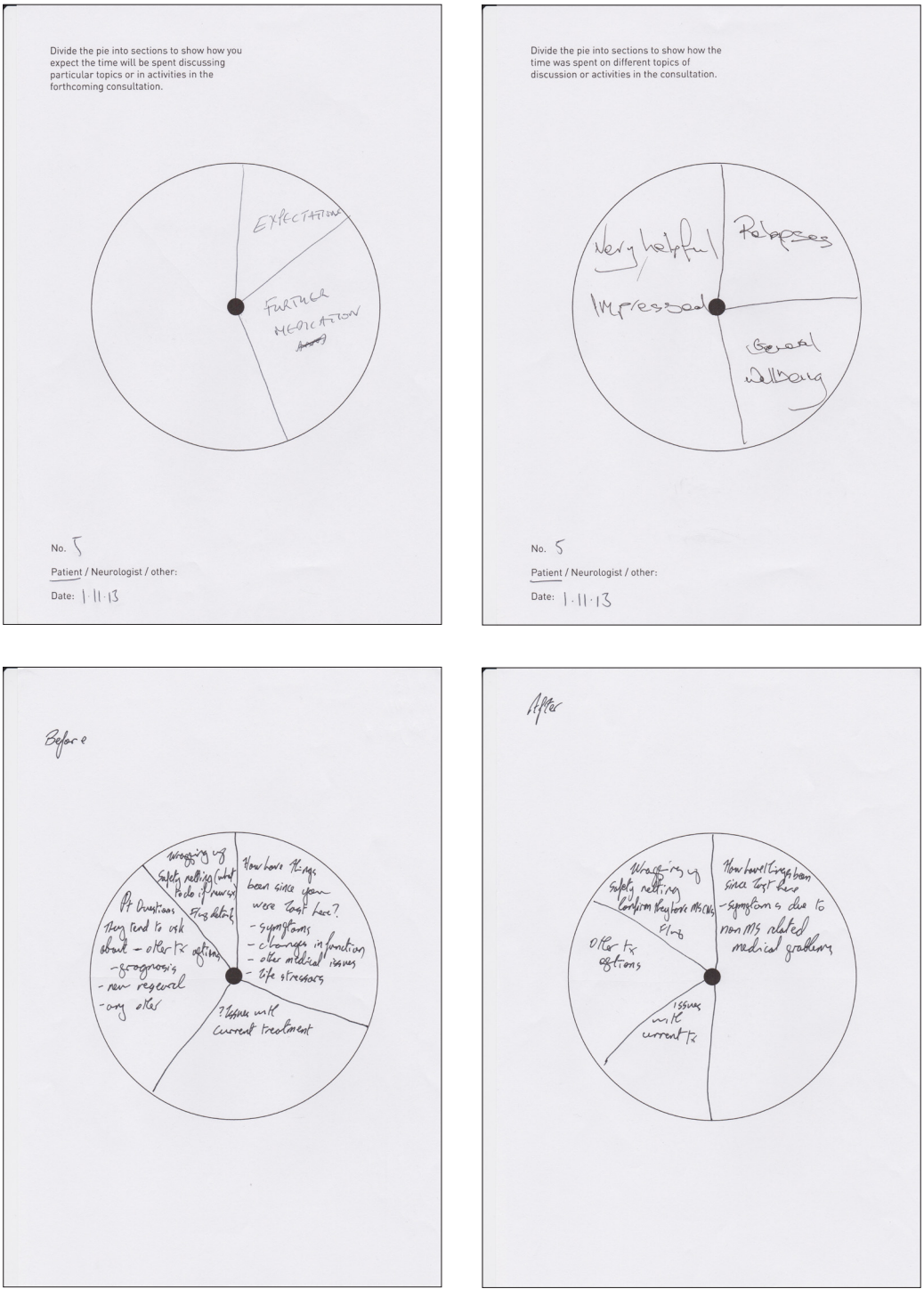


Figure 39 Four scans of the pies completed by Patient 5 and the registrar for the consultation pie activity.

medical work and medical discourse. Yet, both the patient and the neurologist make this an accountable practice (Latour, 1990; Winthereik, van der Ploeg and Berg, 2007).

I see it as a task for design to create technologies of experience to explore ways of thinking together beyond reductionist categories of subjective, objective, quantitative, and qualitative to find ways of working together and explore the techniques people develop and use to validate experience. It also shows how there are other ways to validate experience and create versions which can be accountable to multiple actors.

Accountabilities and assumptions of technologies of experience

Slowing down the data producing site of the clinic exposes a number of competing assumptions and expectations within that clinic within the hospital materials, routine clinical activities and work requirements of healthcare staff to maintain it (Star, 1999; Wiener, 2000). These are infrastructures to keep the clinic working as a technology of experience. This highlights the institutional pressure for patient experience data, the work involved in this process of healthcare staff to collect data, the work dedicated to prove the quality of the service they deliver (Wiener, 2000), and the distributed responsibility to actors (staff, recording tools, medical notes, clinic schedules) in the field. These factors affected how the healthcare professionals completed the pilot study through wanting to do it correctly,[15] its effect on increasing time pressure on the clinic,[16] competing requests from other data-generating tasks and patient expectations to complete correctly under the demand of making healthcare practices accountable takes work (Star and Strauss, 1999). More generally, the material practices observed in the clinic within and around patient consultations are mundane and draw attention to them (through slowing down in the pilot study). They also help disrupt the commonplace production and reproduction of the 'neglected things' of patient experience (Puig de la Bellacasa, 2011, p.100), such as the olive oil. Slowing down shows how design interventions can explore the agendas around patient experience that are enrolled and translated in everyday clinical and healthcare environments (Latimer, 1998). It tells me that producing and generating patient experience makes demands on spaces and material practices in which it is embedded.

This pilot study shows that MS is a situated disease, and medicine is leaving information out through their existing recording and measurement tools. Importantly, things that are left out by medicine can get revealed by other activities.

15 In contrast to the neurologist, the registrar completed the activity with a huge amount of detail including information on every topic that was covered in their discussion. The registrar actually completed the activity twice for this patient, as she was unhappy with how the pie looked once she completed it, she then remade it a second time with different proportions. You cannot tell this from the final image as it is the second version.

16 The neurologist had a long waiting list of patients and was running over time and as such completed the tasks very quickly, stating, 'I need to be quick'.

A new technology of experience

From the analysis of the pilot studies, it has become clear that patient experience is not just a thing that is found, waiting to be measured. It is something that is made. The work involved in performing experience involves not only patients, healthcare professionals, and researchers but also medical measurement tools, representational devices and non-medical objects (including olive oil bottles, plates and emails). Experience technologies can make things transportable, fast and fluid, but in doing this, things get left out. These practices and technologies that make things transportable are taken for granted and are designed to be as frictionless as possible, thereby speeding this process up. I argue that currently, healthcare professionals, researchers and designers working with patient experience do not stop to question what they are doing. The pilot studies have shown how design research can intervene in the making of experience to slow things down to let different experience phenomena come to the surface.

Further, these techniques show how other experience phenomena which have different representations, renderings and expressions can be made valid, even though they come with different assumptions attached to them. Experience is situated in practices that create it and are not transferable in the sense you can give somebody the same experience that somebody else has. If it travels, it creates other things.

The deployment and subsequent analysis of the pilot studies has brought me to the point where I can set up my approach to a different technology of experience. This is a proposal for an alternative treatment of experience through technologies that value different things (e.g., situatedness), ignore transportability and include other things (e.g., does not clean up), and can contribute to different understandings of the treatment, research and care of individual people living with MS.

The interesting thing about my experience technology is that *it* performs experience which is purposefully not transportable. What that means is that it insists on a specific context and specific experience that they are exposing. It can then focus on the properties of staying with the issues and practices that are currently screened out in MS care. Therefore, if design research slows down technologies of experience and the versions of experience they produce, I can then pay attention to other experience phenomena which are valid and do not scale. The question then becomes about how to work with these and what happens if you do not scale experience. Can I make a virtue of them not being transportable? Patient experience has always been approached from a statistical and population-metric perspective with technologies inbuilt and with the assumptions of that type of relationship between the individual case and the data set, as well as the larger population. Arguably, these are bio-political technologies because existing technologies of experience, both from medicine and design, operate to match the individual to the group and work to configure the individual as a population. In other words, how an individual experience matches up with a larger population of people. This scaling happens in design. For example, in medicine, how does

the design of your individual experience match up with a larger population, which is the same approach as in design and can be predicated on mass production and taking the individual user (Wilkie, 2010) as a proxy for populations of people. However, I am saying something different. Instead, I am proposing that, instead of matching people to a group, there are opportunities to pay attention to experiences that do not fit and do not scale. These experiences will tell you something else. At this point in the thesis, I can now start to explore the implications for designers working within healthcare settings (maybe they need to think about designing slower experience technologies).

Conclusion

The pilot studies presented in this chapter have investigated specific points of investigation and pulled out a number of new learnings about working and researching patient experience. It has uncovered that in trying to make experience transportable, crucial information is left out. This provides an opportunity for people that work in and research this field to pay attention to experiences that might not scale and make more out of what is getting left out.

The chapter has described and analysed bespoke design interventions deployed as practice-based designs. In doing this, it has attempted to make the case that it is in designers' interest to intervene in the creation of experience. It can suggest alternative ways to think about and approach experience while also contributing to medical and scientific understandings. In saying this, these were initial design experiments where some worked better than others in accessing the object of study. In this deployment process, I learned that design leaves information out too. This is an important point.

Chapter 5: MOT – A study slowing down technology of experience

This final empirical chapter describes practice-led design studies of patient experience-in-the-making through the stages of developing a new technology of experience. This work continues with the approach introduced in the previous chapter of slowing down to think through how new associations and arrangements of patients, researchers, healthcare professionals, designers, technologies of experience and experience phenomena can produce and bring into being different versions of patient experience. By continuing to do this, I can reconsider how patient experience is made and what it is made up of. I can also start to consider the potential implications of these new ontological compositions. By continuing this commitment to work with those affected by this research issue, specifically the experience phenomena that emerge by way of my research practices, it becomes a speculative obligation. This is speculative as this process does not define in advance what the end result of this process is or what it *could be*. This research process has brought me to the point where I am tasked with exploring the potential of working with experience phenomena through performative research events.

This chapter starts with a brief description of the setting of the Measurement on Our Terms (MOT) study,[1] describing how I brought people with MS together to discuss how their upper-limb function is affected by their MS. This is the final piece of research practice in this thesis. I use the analysis of the material produced through these research activities to develop my model for a new technology of experience that started in the previous pilot study chapter. In this chapter, descriptions of what happened in these research activities will be framed through the lens of the following theoretical instances: MS ensembles (a term introduced later in this chapter), homegrown technologies, artefacts as entry points, non-transferable experiences and frictions. Each section will include analytic discussions which draw on accounts, findings and reflections from the activities. This will allow me to develop the model to see how it does or does not work with this new material. The chapter will end with a discussion on directions for the future of the research and implications for my understanding of working with patient experience through design-led research.

Working towards a new technology of experience

As previously described in this thesis, PROMs are technologies of experience in that they produce and circulate specific versions of experience that hold certain assumptions about the nature of experience, subjectivity and what it means to be human. Slowing down the process by which medical technologies of experiences are developed will allow me to pay close attention to the practices and assumptions within each procedural stage of PROM development. This includes specific objects, tools, phenomenon, processes, spaces and

1 The study name, Measurement on our Terms, was developed by the Barts MS advisory group who were consulted on the development of this study in August 2017. The title is intended to reflect the perspective of people with MS having previously been not involved in PROM development activities. It is to show that I am interested in working with people's experiences on their terms, instead of those set by medicine or science. The phrase 'on our terms' has been used in mental health participatory research (Gillard et al., 2012).

bodies involved in their creation. This is a speculative exploration in that I am now not aiming to produce a new PROM tool or questionnaire to measure or capture patient experience but instead aim to explore the techniques of developing a new technology to see what the potential for an alternative type of technology of experience could be. Therefore, this research is interested in addressing the characteristics and assumptions inherent in existing medical and healthcare technologies: for example, the assumption that the unit of measurement is pre-existent, that some entities are excluded, and that versions remain unchanged by tools to gather and create it.

To research these different practices, assumptions and versions within the PROM development process I developed and ran the MOT study. The medical PROM development process involves patients in limited roles of producing **Experience 1** and commenting on the dissemination format. However, involving patients directly in my study enables me to work with an expanded notion of experience relatively free from assumptions while being able to consider how the participant's direct involvement can contribute to new understandings of working with different versions of experience. This is aligned with current PPI practices in healthcare research of involving patients throughout the research process to contribute in more inclusive, collaborative and democratic ways as well as co-design and participatory design practices. Further, involving people with MS is an exciting opportunity to explore both the administrative and regulatory research practices of involving people who are not researchers or clinicians in a research activity based in healthcare and involving design, as well as the theoretical possibilities and practical issues of working with patients.

MOT study overview

The MOT study consists of three meetings and one online survey shown in Figure 40. These were roughly modelled on the medical PROM development process of item generation (collecting new activities to measure), item reduction (reducing activities to a manageable number) and psychometric measures (calculations on internal validity amongst other things) (Hobart and Cano, 2009). The medical PROM development process values characteristics of replicability, scalability, and anonymisation to ensure that the measure is coherent and can measure patient populations (Dowrick et al., 2015).

The MOT study ran from November 2017 to January 2018 and was held in The Unity Kitchen community café, a location not associated with the hospital or the university in East London (Figure 41 and Figure 42). The three meetings involved ten participants whose hand and arm function are affected by their MS.[2] These people can be considered patients in this context since they are seen as patients of the MS service at the Royal London Hospital.

2 I intended to include between ten and twelve people in the meetings. The selection criteria is outlined in the study protocol (Appendix C) which describes the requirements for people to take part, along with the resources, research techniques and equipment that you need to run the project. The purpose of this was to ensure that they could in fact discuss an experience of their upper limb being affected by their MS. Marc Berg compares the protocol document to a form of scripting of the research process (Berg, 1997).

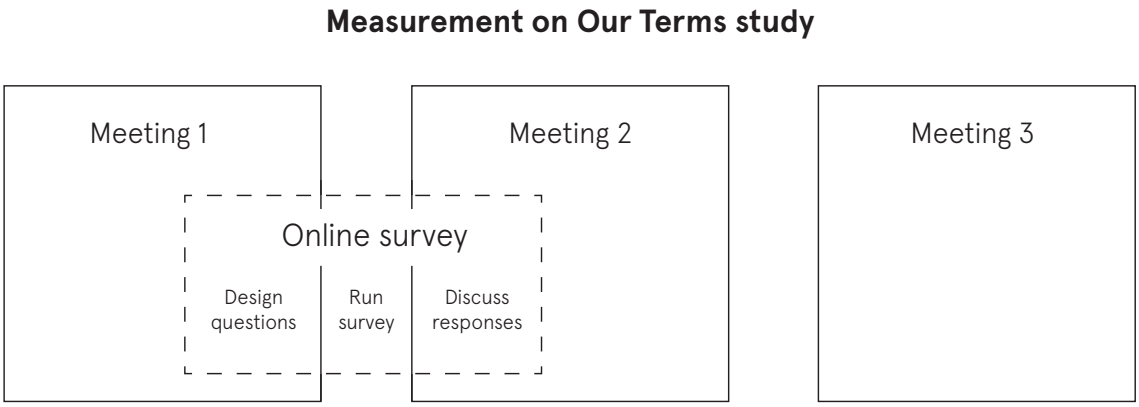


Figure 40 Diagram showing how the two groups of patients interact in the face-to-face meetings involving 10 people and the online survey which received 89 responses.

Figure 41 Photograph of the Unity Kitchen Café where the meetings took place. The photographs are taken before the meeting when the participants were not present. I did not have ethical approval to take photographs of participants in the space.

Figure 42 Photograph of the view from the Unity Kitchen Café in the Olympic park, London.

Therefore, the study sought and successfully received National Research Ethics Service (17/LO/1684, Appendix D) and QMUL (QMERC2017/52, Appendix E) ethical approval, QMUL sponsorship (Appendix F)[3] and Health Research Authority approval (IRAS project ID: 228062, Appendix G).[4]

In the first meeting, patients verbally shared activities where MS affected their hand and arm function in response to some opening questions (Appendix J). The participants shared accounts of situations, challenges and techniques of everyday life living with MS. They were curious about other people doing similar things, so we designed questions to ask a larger group of people through an online survey. The questions were:

1. **What hand and arm (upper limb) activities do you find difficult, due to your MS?**
2. **What external factors affect how you complete these activities?**
3. **Are there any tips, hacks, devices or tools you use to help you complete any of these activities?**
4. **Are there any upper limb activities that you avoid doing?**

The survey was posted on the Barts MS research blog (Figure 43) and received 89 survey responses over three weeks from readers whose hand and arm function is affected by their MS.[5] This took place in between the first and second face-to-face meetings.

From the responses of the 89 survey participants, I brought the most frequent 24 activities in response to question 1 to the patients in the second meeting (Figure 44), and they reviewed them with the most frequent external factors shown in Figure 45, which were responses to question 2. A full listing of the data gathered and categorised into activity groups and external factors is presented in Appendix K and Appendix L.

At the second meeting, the participants discussed these activities in two groups aided by an object to represent each activity (Figure 46). They selected and categorised the top three external factors that would have the biggest impact on them completing each activity. The purpose of this was to replicate how traditional PROMs reduce **Experience 1** through psychometric calculations. Instead of this reduction happening through calculations, I let

3 There were many conversations about which institution would sponsor the study (i.e., take legal responsibility for the project). My professional role, and where I conduct my practice-based work, is based in QMUL, but the study would be included in this thesis, which is registered at Goldsmiths. It was concluded that QMUL would sponsor the study as they had existing links with Barts Health NHS Trust where the patients are treated. I think this situation is important to include here because it highlights the procedural issues that need to be navigated and addressed to carry out this work.

4 Recruitment for the study was conducted through the Barts MS service at the Royal London Hospital in Whitechapel. Clinicians of this service suggested patients who met the inclusion criteria and would likely be interested in taking part. Once I had their phone numbers and email addresses, I contacted them individually to share the participant information booklet (Appendix H) and consent form (Appendix I) which was signed at the beginning of the first meeting. Potential participants then confirmed their interest and their availability to attend the meeting dates. The recruitment process took eight days.

5 The Barts MS Research Blog itself is an interesting technology of experience in how it mediates patient experience amongst health-care professionals, MS researchers, pharmaceutical companies, charities and people with MS and their families. The role of digital technologies in medical interactions related to patient knowledge, expertise and experience is discussed elsewhere (Vennik et al. 2014; Speed, Davison, and Gunnell 2016; Dudhwala et al. 2017).

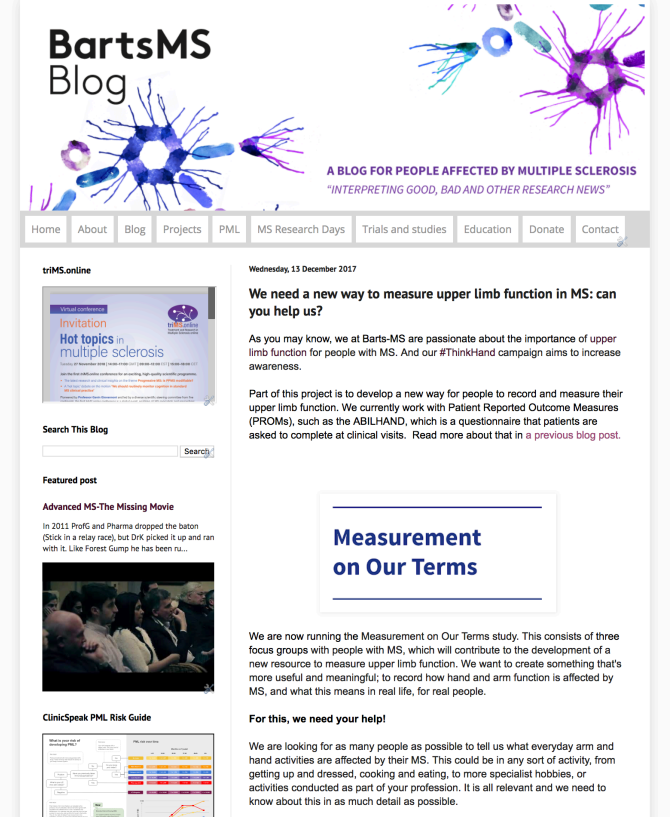


Figure 43 Screenshot of the MOT survey on the Barts MS Blog 13th December 2017 (Source: Thomson, A. (2017). We need a new way to measure upper limb function in MS: can you help us?. [Blog] Barts MS Research Blog. Available at: http://multiple-sclerosis-research.blogspot.com/2017/12/we-need-new-way-to-measure-upper-limb.html [Accessed 13 Dec. 2017]).

Activity	What hand and arm (upper limb) activities do you find difficult, due to your MS?
1	Opening crisps
2	Knife and fork
3	Carrying liquids
4	Dealing with coins
5	Pills out a blister pack
6	Changing sheets
7	Tying shoe laces
8	Sewing
9	Using keys
10	Playing piano / guitar / instrument
11	Lifting heavy pots while cooking
12	Hair; washing, drying, brushing, straightning
13	Typing
14	Touchscreen tech.
15	Handwritting
16	Putting on Jewellery
17	Make up
18	Putting on a bra
19	Opening a jar
20	Chopping vegetables
21	Getting dressed
22	Carry heavy plates
23	Buttons
24	Heavy kettle

Figure 44 The 24 top activities gathered from the MOT online survey.

What external factors affect how you complete upper limb activities?	
External Factor 1	Time of day
External Factor 2	Duration of activity
External Factor 3	Temperature
External Factor 4	Visibility
External Factor 5	Emotion
External Factor 6	Being watched
External Factor 7	The activity before
External Factor 8	Other

Figure 45 The top 8 external factors gathered from the MOT online survey.

Figure 46 Activity objects displayed on the table in the meeting.

patients decide which activities to 'other'. In the third meeting, we collated the discussions by counting the frequency of each external factor featured in the top three of an activity. This activity was recorded visually on a series of display signs that displayed one external factor per sign (Figure 47 and Figure 48). The study concluded with a discussion of potential new ways to measure upper-limb function at home.

This next section pulls together the responses from what happened when patients were brought together around the proposal of developing a new technology of experience. Each section describes an overview of what happened, a demonstration from the data and analysis.

MS experience ensembles

The assumption that healthcare staff, researchers and designers can process the experiences of people with MS has now been positioned as problematic by this thesis. One of the primary motivations to work with patients directly in this final piece of research is to uncover exactly how patients can contribute to a technology of experience or provide material to participate through it.

In the discussions, patient participants shared accounts of having temporarily or permanently lost lower- and upper-limb function. In great detail, they explain the effort and organisation involved for them to complete everyday activities of getting dressed, eating, interacting with others, moving about their homes, caring for their children, and so on. They shared examples of the struggles to complete very specific tasks of fastening buttons on a shirt, fastening earrings, writing with a pen, cutting food, handling spaghetti with a fork, tying shoe laces, and more.

> I find eating food and handling cutlery increasingly difficult. Handling a knife just ends up slipping and turning in your hand when trying to cut things. It's very strange actually, just trying to get to get food to your mouth. That sort of action [brings hand to mouth] is still very hit and miss. **Participant 1, meeting 1.**

> Although you see me now making notes, writing should be avoided at all costs. I'll use the PC. Writing for literally a few minutes and I can't read my own writing. **Participant 6, meeting 1.**

> Give up the idea of swirling spaghetti. **Participant 7, meeting 1.**

Some of these activities were shared by more than one participant, whereas others were unique to individuals. Patients who responded through the online survey shared similar accounts of these everyday activities.

Figure 47 Close up photograph of the external factor signs. The top three most influential external factors were selected per activity and ordered in first (blue dot), second (orange dot) and third (black dot) level of importance.

Figure 48 Photograph of the external factor signs.

> While I can type and knit I cannot do it for any length of time. My hand can be quite painful if I do too much. It is quite restricting. Holding a needle to sew is very difficult as I cannot feel the needle with my fingers. **Survey respondent 22.**

> Difficulty using hair dryer and brushing/combing hair, some days I cannot lift my arms high enough and find the hair dryer too heavy to hold steady. **Survey respondent 65.**

> Writing, small buttons, putting on earrings and necklace, hand tires quickly so struggle to eat pudding and main, putting on makeup, picking up coins/small objects, measuring pulse (can't feel it), sewing. Doing hair (arm tires easily), hanging out washing (arm tires after a few items). **Survey respondent 4.**

Both groups of patients described the objects, or experience phenomena, involved in supporting them to complete these tasks – using wheelchairs, using cutlery, using technology software, using gadgets, using the floor or chairs to help them put on trousers and also using other people such as partners, other family members or professional carers. Three participants attended the meetings with a family member and one with a professional carer to support them in their involvement.[6] The important role of the carers is exposed in the meeting where a partner as a carer describes that 'Yes, we see an MS Nurse' in their routine care, including herself as part of the patient ensemble that is affected by MS.

A significant part of the discussion was around other things that affect their ability to take part in the rigours of daily life, which they termed 'external factors'. These included the temperature of the room they were in or a hot summer, visibility in a space or at night, being watched and the fear of dropping something, or time of day that they were completing the activity (as they have more energy in the morning). Below are some examples from the meeting discussions and the survey responses around the external factor 'time of day'.

> I find it hard doing up buttons. Doing up my eldest daughter's dresses. She always comes to me "can you do up the button on the back." Typically, she's going to ask me at 7, 7.30 at night or whenever and it's just impossible. If she asked me at 7 in the morning I'm normally able

6 Most notably, one participant did not have any hand or arm ability and had full-time professional carers. Interestingly, this participant should not have been involved in the study since her MS was too severe, according to the inclusion criteria of the study. However, her clinician highly recommended I invite her because she is still able to work as a jeweller supported by technicians. This participant could attend the meeting because she was supported by a professional carer throughout the project.

to but when we get to 7 at night it's a bit more of a chore. **Participant 2, meeting 1.**

The evening is worse, when I am tired. **Survey respondent 41.**

Worse as day goes on. Much better first thing in the am. **Survey respondent 43.**

Left side does not function when tired so need help afternoons and evenings. **Survey respondent 54.**

These external factors are situated and contextual. Although hard to quantify, each person had to take them seriously. The discussion below demonstrates how the risk of fatigue makes managing the external factors priority in everyday life.

Participant 1: I found there is ways you can save energy for something else you're going to have to do. Save energy. You know I have a limited amount of energy available and have to use it sparingly, or choose how you use it.
Participant 5: If you can do it, do it.
Participant 1: You need to try and preserve the energy you have.

Another example was that 'being watched matters'. Because people must simultaneously assess the uncertainty of the activity, their bodies and the situation, the addition of being watched only adds to the pressure of the situation. One participant felt fine drinking a pint of water at home, but felt very self conscious drinking a pint in the pub in the fear that they would drop it in front of people. It is important to remember that the MS ensemble produces the careful person in the pub. In these examples, bodies and specific external factors all play a part in how these ensembles are performed (Mol, 2002).

It was surprising that these external factors had been experienced by all the participants but affected each one of them slightly differently within each activity. For example, none of the participants could function after taking a hot bath or shower or in hot weather because they were affected by the heat.[7]

7 People with MS are unable to control their core, or inner body, temperature as temperature control is part of the autonomic nervous system, which is affected by MS. This has a major impact on the functioning of their nerves which become sensitive to temperature and block or stop conducting at even modest rises in core body temperature (Romberg et al., 2012).

I find the hot weather really difficult, you just get wiped out. **Participant 8, meeting 2.**

I'm more tired after being in a hot bath. **Participant 7, meeting 2.**

If I get out a hot shower I can't do anything. **Participant 5, meeting 2.**

The temperature also affected many of the survey respondents.

Heat. **Survey respondent 43.**

If it's hot weather I feel very fatigued. **Survey respondent 5.**

When it's very hot I find everything more difficult. **Survey respondent 77.**

Patients are aware of the capacities of their bodies, which are enhanced or not by machines or people, and where they can and cannot circulate. What became clear early on in the discussions with patients is that people with MS were aware of the work involved just existing as a person. In these accounts, it becomes clear that these people depend on the network of different entities – the floor, chairs, carers – to take part in the rigours of daily life. If thought about as hybrid collectives (Callon and Rabeharisoa, 2004) or *MS ensembles*, it shows how action is distributed across human and non-human networks that are adapted for their survival with all the articulation and connections required. Everything must work meticulously together in the ensemble between people with MS, their bodies, others bodies, technologies, objects and tools around them just to perform everyday tasks. These are ceaseless practices, hidden labours and situated actions (Suchman, 2007) to maintain everyday life, where things work as a network of care to enable them to complete tasks.[8] I initially did not comprehend the demand it took on their bodies and energy to do this nor their commitment to complete the simplest of activities. The limit of the MS ensembles became apparent when one of the partners had a cold and decided not to take part in the meeting so as not to spread germs amongst the participants with MS. This would have been high risk to those with weakened immune systems as this could cause a relapse of their MS. Here, she has to account for her body as part of the MS ensemble she is part of, and the other ones in the session.

8 Moser (2006) points out that disability is ordered and performed in situated and particular ways and importantly for this thesis, material objects have a role in enabling or limiting interactions. Further, focussing on taken-for-granted stories is a common strategy for scholars of feminist science and technology studies (Latour, 1987; Star, 1990; Suchman, 1995; Star, 1999; Bowker and Star, 2000). By doing this, I am enabled to unpack the invisible work requirements that make up this taken-for-granted work, of living as a person with MS.

These accounts make me aware of the maintenance that is required everyday to live and how they constantly have to deal with and take into account many factors and make a number of decisions before they do things many people would take for granted. This is different work to that of doing patient experience, as these accounts describe the work involved in just being a person with MS before they can even be captured by a technology of experience (such as in a questionnaire, or an interview). But what this highlights for my understanding of patient experience is that the examples of patient experience discussed in this thesis so far have the assumption that experience is being performed for other people – healthcare professionals, researchers and designers – to access and utilise. What these accounts of experience do not consider or account for is any of the upfront work patients are already engaged in. This work not only enables these people to exist and function, but it also enables them to participate in this study as participants. I experienced a glimpse of this demand when the cups the meeting venue provided had no handles. A partner of a person with MS pointed out that we needed to change them because the patients could not use them without a handle. This work enabled them to attend this meeting and tell me their accounts to make patient experience – **Experience 1.**

This pre-capture information then becomes interesting to turn into patient experience, as it has not yet been cleaned up by any technology of experience and probably is the stuff that normal measures of patient experience do not actually get at. This material may not pertain to innovative outcome development or scientific expertise, but as Haraway (2008) points out, it is the mundane and the ordinary that helps understand what kinds of worlds are being made (and unmade). In healthcare research, this requires attention to the role of the mundane, everyday materials and practices of these people's lives to make their worlds (Latimer, 2018, p. 379). It also shows an awareness of the problems that concern patients, and does not take this for granted. The exclusion of what does not count according to medical research is seen in how the carer's role is not considered as a valid part of patient experience by the research ethics team, as they were not considered to be part of the meeting. So, the question of whether they should grant informed consent did not arise. However, without them, many of the MS ensembles would not have been able to participate.

Another point here is that patients brought forward external factors which affect both them and their MS ensembles. Here, it is not just that time of day is important, but that the patient's involvement in this process has demonstrated how these factors need to be part of working towards a new technology of experience. It is clear that the participants value them and take them seriously, so should not the research community also? I suggest here that perhaps a technology of experience needs to look at people's skill in recognising and working with these external factors. Thinking back to how work practices of healthcare staff is erased from **Experience 2** in the clinic, it is important that patient work and skill are not erased.

Homegrown technologies of experience

An important assumption for existing technologies of experience is that experience is transportable, fluid, friction-free and fast. This study works with the mess and what is left out of medical versions of patient experience. In slowing down the process of PROM development in these encounters with patients, I take a closer look at how exactly things are included, considered as valid or excluded. The pilot studies showed how non-medical objects, such as olive oil bottles, can be validated as an object of experience by a clinician and patient in the clinical setting; and the scientific validation process has been written about elsewhere (Shapin and Schaffer, 1985), but what about in different settings of the everyday lives of people with MS.

Participants shared their stories in the discussions and the survey of how their MS affects their hand and arm activities. A number of examples came forward, demonstrating a practical knowledge of managing activities.[9] These included using dictation software to write emails, opening a packet of crisps with scissors, buttoning up a shirt before putting it on, and buying pre-cut frozen butternut squash rather than having to cut it yourself.

Participant 6: I work in an office, I'm still working and I wear shirts all day. I have a few remedies I found is one when I take this shirt off…

Participant 2: Leave it done up?

Participant 6: This button (top) gets undone, the rest stay done. It goes in the wash and it stays that way. I have been known to spend 5 minutes, especially the top one, not the very top, the next one down, because you can't see it. So frustrating. So a little gadget and it's got a little loop, like a paperclip sort of metal which you put through the button hole. It hooks the button up and you pull it back out and I can do that in seconds. Very very useful.

Participant 7: Didn't know they worked.

At the next meeting the same participant reported the below:

Participant 7: [Participant 6] said about the button tool, so I bought one. I was saying earlier that I can do buttons up now!

9 See Appendix M for practical examples collected through the online survey.

They also, interestingly, shared examples of activities they conduct regularly to measure experience for themselves. One participant shared an activity he completes everyday and uses to tell how his hand function is changing:

> I eat a yoghurt most days and things like using a small teaspoon to clean out the bottom of the yoghurt pot is impossible to turn it and do that action [gesturing a wrist turn movement]. It's just one of those things it's not so difficult that I can't eat them. Just sometimes you notice and you think, that's getting more difficult. It's just an observation when your scraping out the last bits. **Participant 1, meeting 3.**

Similarly, another participant shared their experience of seeing the change in their painting:

> I'm right handed, I feel things with my left arm and generally I'm quite a broad painter, I'm not going to … but I used to be a mathematician, partly because in art I can be messy, you don't have to be so tidy. So, I'm not worried because if I lose fine movements, I'll start painting in different ways. I already see changes in my brush strokes. **Participant 3, meeting 3.**

Here they discover what their bodies are capable of in the process of adopting mitigating tactics. These examples show patients' ways of working with their bodies and within their MS ensembles is through practical interactions involving experiments and tests with everyday objects found in their homes. Pols (2014) frames patient knowledge, developed out of routine practices in their everyday lives, as practical knowledge which considers how patients use medical forms of knowledge to work with what they know and do. As practical knowledge, it aims to improve daily life of people living with disease (Mol, 2006). Patients have developed knowledge and techniques to interpret and shape their daily lives with a disease to 'cope'. Coping here is a matter of adjusting, coordinating, gaining advice, and testing. This is a messy type of knowledge involving a variety of different things. This is in contrast to the medical way of working with patient experience through knowledge and knowledge practices. In the button example, one technique for one person is shared practically and becomes valid for someone else. This has also been seen in examples of Chronic Obstructive Pulmonary Disease (COPD) patients (Pols, 2005) and patients with muscular dystrophies (Callon and Rabeharisoa, 2004) transferring practical knowledge. The point is not to privilege patient accounts over medical versions but to analyse the utility of these accounts for understanding patient experience and how it is done. What is interesting

for this thesis is that a practical way of knowing is more akin to design with similar approaches to generating knowledge that are also practice based.

The yoghurt pot tests and the painting examples can be thought of as a home-grown technology of experience or practices of everyday monitoring. They have developed a situated personal measure of how their MS is doing out of everyday activities. Pols describes this type of knowledge as a form of 'know-now' (Pols, 2014, p. 80) as they are situated activities of knowing. These practices are developed between interactions of their bodies, their environment and other objects framed in this way to produce knowledge of their MS and bodily functions. The practices simultaneously mitigate and produce knowledge about MS. Unlike medical and scientific measures, it is not separated from the everyday flows of life. Importantly, this information is for themselves. If we go back to Ellwood's description of the purpose of technologies of experience in that they were originally intended for patients to make decisions about what to do or change, then this example demonstrates how patients are currently using their everyday activities to capture, process and format their experience. Facilitating this discussion in the study enabled the patient to circulate it to another patient who was then able to validate it for themselves in their home and returned to report on it.

Techniques invented locally may not travel beyond the places of their creation and so become problematic for medicine since they cannot be used for care. One design proposal would be to make them transportable as a resource, which leads me to think about proposals to collect these techniques and make them available to others. This would need to be done not through methods of medicine, but through design methods of practice.

However, if I take a different direction and do not see what is generated as a resource, then what can it be used for? Well, the patients have put forward their accounts of purpose – a useful tool to help patients articulate change in their daily lives. So, if everyday practices are supported to exist and circulate, and not put under pressure to be cleaned up or scaled, then they could supplement clinical data. Mol (2006) suggests the notion of tinkering to show how healthcare professionals and patients together can come to specific standards for medical practices which are valid and accountable for patients' specific situations. These articulations could contribute to this area. In other words, these specific, situated patient practices – involving external factors and mitigating strategies – give a view of patient experience that is different from (and perhaps a more accurate reflection than) those given by traditional clinical experience technologies. Following Mol, I argue that these should be allowed to exist without trying to convert it into a (traditional) experience technology. This would be a more practical, everyday consideration of experience brought forward in everyday interactions and be closer to thinking through a lens of care (Puig de la Bellacasa, 2017; Latimer, 2018). Thinking about experience through care exposes the need for changing

how science and technology, medicine and healthcare are produced. I explore this further later in this chapter.

MS is a disease that fluctuates daily, changing either through relapses or in progression over time, making living with a changing body and everyday negotiations crucially important. It needs to be re-done daily in changing situations. Being able to know what you are capable of one day, and not the next, is something that people with MS and other degenerative diseases will be used to. However, it poses specific challenges for ways of measuring and reporting in sporadic annual medical visits. The proposal of a technology of experience that patients can use at home to report on where they are suggests a hopeful way of reporting on their experience. What this means is that technologies of experience need to work and adapt to situations far more varied than the clinic or the scientific conference and to places such as kitchens in people's homes, the pub, workplace offices and artist studios. These situations are where people with MS need approaches to diagnose a situation and find out how to react to it.

Artefacts as entry points to experience

By opening up the PROM development process, I can compare the knowledge practices of medicine and healthcare research to the practice-based approach of design research. Accounts of everyday practices of living with MS feature heavily in patient discussions and also in the role of objects and artefacts. This study foregrounded practice as a way to further articulate the focus of research (patient experience), taking a closer look at the socio-material conditions (tools, practices, methods) for bringing new versions of experience into being through the discussions and accounts of patients. This picks up on the findings from the previous chapter to further explore how exactly non-medical objects can become included as valid versions of patient experience.

I took the accounts from the group and the survey and presented this back to the group through physical displays (Figure 49). They were specific in their description of the activity and specified a material constraint of the specific object presented in the meeting space (i.e., not the home). The purpose of displaying the objects that are involved in these activities was to further explore the role of the object in these accounts and to be a technique to help participants express their ideas about measurement.

The objects presented on the table, although proxies, have been brought into discussions about patient experience through their accounts. They represent activities and interactions which have come into being through the discussions to uncover and represent different realities of MS (Mol, 2002, p. 5).

There were two purposes of introducing the objects in the second meeting. Firstly, as people reported problems with specific activities that involved different MS ensembles, they commonly included specific objects such as laces, needles, coins, and keys in their descriptions. However, with this, there is ambiguity around what type of shoe or size of

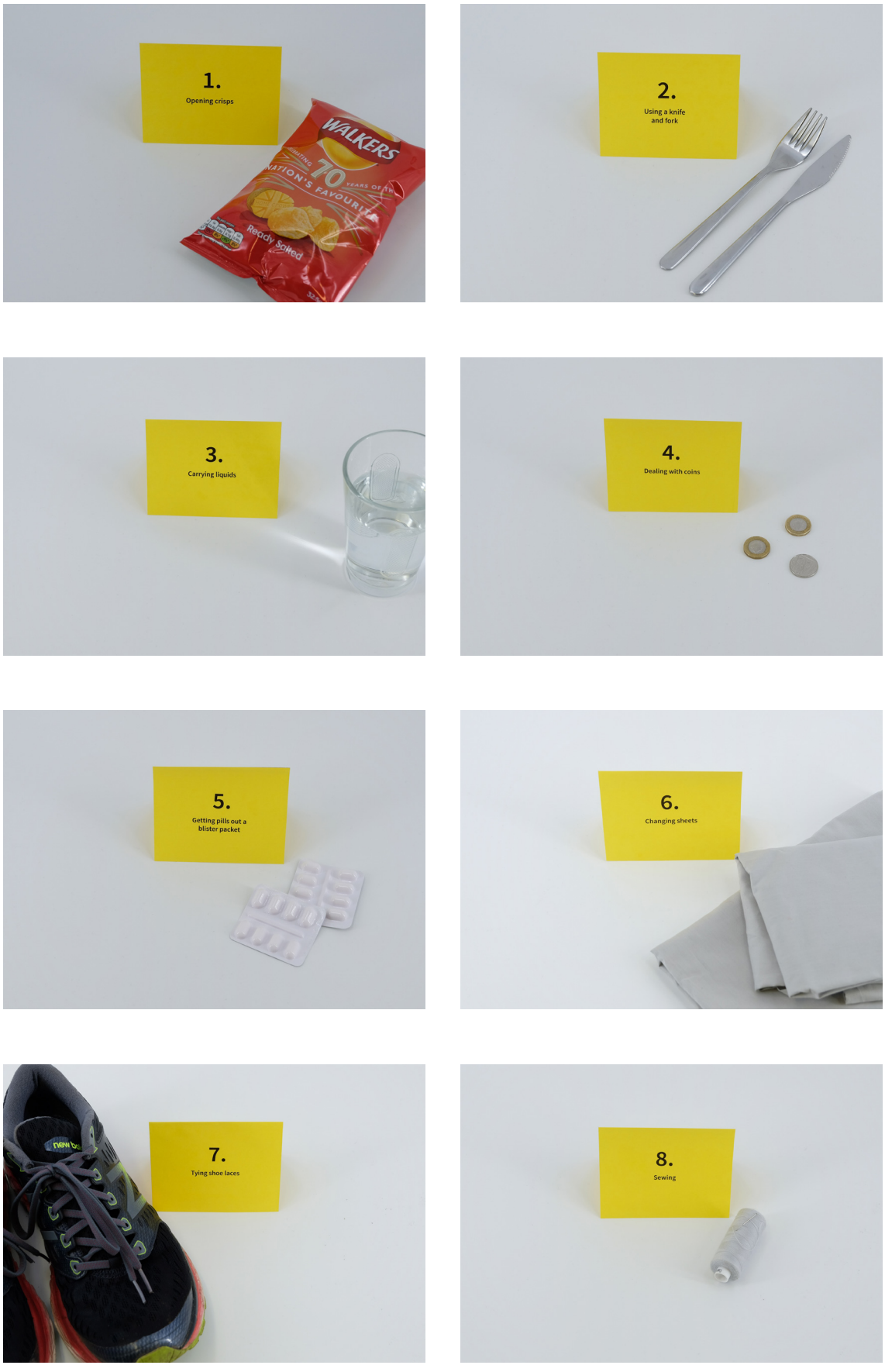
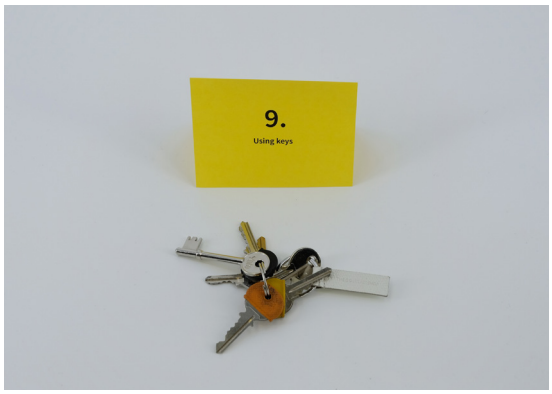


Figure 49 Photographs of the objects displayed in the second meeting.


9.
Using keys


10.
Playing an instrument


11.
Lifting heavy pots while cooking


12.
Hair: washing, brushing, drying
BaByliss
ProGrip


13.
Typing on a keyboard
logitech


14.
Touchscreen

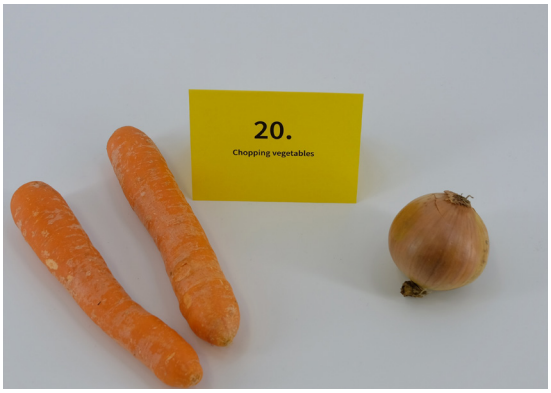

15.
Handwritting
A very short sentence


16.
Putting on jewellery


17.
Applying make-up


18.
Putting on a bra


19.
Opening a jar


20.
Chopping vegetables


21.
Getting dressed


22.
Carrying heavy
plates


23.
Buttons


24.
Pouring a kettle
BOSCH

needle, or type of keys for which lock. Secondly, patients suggested involving physical artefact representations of the activities in the meeting in a preliminary activity for people to use, manipulate or touch, if they wanted, to help articulate their descriptions. In the designing the study activities, I have to be mindful of the capacities of the people involved and their potentially limited ability to interact with any physical activities or tasks presented to them. Therefore, it was important not to limit them to contribute ideas only physically, but to allow verbal responses and the possibility of interacting with these objects.[10] I was aware of other studies in design which have found that people with physical and cognitive impairments struggle with probe-drawing activities provided by design teams (Smeenk, Sturm and Eggen, 2018). Therefore, I limited responses to verbal contributions.

What happened was unexpected. Through these activities, I found that the simulation of activities with these objects did not work in the meeting. Patients did not touch or manipulate the objects nor comment on their specific design. They described activities of opening a packet of crisps, using a knife and fork, carrying liquids, dealing with coins, changing bed sheets, typing on a computer, sewing, using keys, and so on. However, it was not this specific set of keys or this hairbrush on the table that they would struggle to use. Them using keys in their homes gives rise to a practice with accountabilities that are linked to their MS ensembles. By placing the keys or an example keyboard on the table, it then becomes isolated from any ensemble or 'bracketed out' (Mol, 2002, p. 36). This is because it is different from the object at home and also not in the usual context of use. Objects in practice are not the same from one site to another. The situation at home triggers other ways of behaving than the situation in this meeting or in clinics for example. Clinics are about organisation and cleanliness, this meeting was about groups of people coming together to discuss and give feedback, the home is about comfort and probably involves family members and friends.

This goes back to the discussion in the earlier chapter around practices of simulation and the utility of recreating bodily practices for the purpose of measurement. In the pilot study, clinicians were walking patients to measure their optimum distance in front of them and with validated medical tools. Here, I am similarly asking patients to do the same. The lack of response to this activity supports the findings of the pilot studies in showing that patients do not engage in simulation. I know now that MS ensembles do not engage in simulations because the objects presented were not situated and were stripped out of their ensembles (i.e., it was not their keys nor was it their usual setting).

The variety of objects show how almost anything can be part of an MS ensemble since everything has the capacity to be painful and problematic, everything has capacity to be a struggle (Moser, 2006), and therefore tell you something about your MS. In addition, it can

10 This is unlike many participatory activities in design research which commonly ask people to write responses down on some form of paper tool (Knutz, Markussen and Thomsen, 2018).

be part of the practice of experience. Unexpectedly, the objects on the table became an entry point in thinking and talking about a situated activity with certain types of conditions and factors, where the object acts as proxies for generalised activities. What this tells me is that patient experience can be brought forward through specific artefacts and not just human reporting. This is an important finding as it adds to the limits of **Experience 1** which is limited to cognitive reporting. This work shows that patient experience does not sit in people's heads, in protocol documents or in textbooks. It is part of practices, devices and situations.

I think it might be helpful here just to clarify that working with a situated experience is different from working with a subjective experience – which would be a human-centred cognitive entity. I am making the point that experience can be brought forward through artefacts, not just human reporting, which I think contributes to the discussions in co-design where ANT has been celebrated for its ability to explain how materials and artefacts always play a role as non-humans determining how people and materials participate in collaborative activities (Eriksen, 2012).

So, what does this mean for healthcare design? What was interesting was the participant's reflections on objects that had been adapted in their design to try to compensate for their lack of upper-limb function to, for example help with reduced grip strength or dexterity. Products such as the OXO range and thicker cutlery were described as 'useless' because they made a presumption that if the physical impairment was subsidised by a product, then the task could become achievable. This leads me to question the success of these designs for this group of people. What was discussed to be a more productive suggestion was that their hacks around activities be shared. Here, design has made assumptions about MS bodies and ensembles and what they are and are not capable of. Therefore, this is a different role for design; rather, in trying to compensate, design should work to support existing MS ensembles to produce experiences they want to produce and find interesting and useful.

Non-transferable experience

A key stage in the translation of experience within a technology is the generalisation and reduction of data to become visualised. The purpose of this attempts to formalise and scale this version of experience. In the meeting, participants discussed how they complete activities and then compared them to accounts from other patients from the survey data. It became clear through these discussions when comparing others' activities and personal choices to their own experiences that there are a number of different ways to do things. This is for a number of reasons – external factors affected people differently, there are different

ways of completing each activity, some activities are irrelevant to some people, and different people had different priorities.

Participant 1: Yeah I mean there are some things you want to do yourself.
Participant 4: Do you have to wear a shirt?
Participant 6: I work full-time, I literally just came from work.
Participant 4: Do you have to wear a shirt?
Participant 6: I can get away with not wearing a tie, but not a shirt.
Participant 4: Smart casual?
Participant 6: Fridays I would say.
Participant 4: Do the people in the office know your situation?
Participant 6: Yes.
Participant 4: I'm sure they wouldn't mind, if you didn't wear a shirt.
Participant 6: I just choose to try and stay the same as much as I can. People say, "Why are you working?" and I intend to stay working as long as I can. There's no other reason for it. Personal choice.

Combining the responses of the survey with those of the patients enabled a deeper discussion to take place where patients expressed anger, humour and disagreement. This actually became the source of tension and disagreement where some of the suggested activities brought forward from the survey were rejected by the patients in the meeting and asked to be removed from any future way of measuring your function, such as when taking pills from the packet was considered not valid as it was 'too difficult to measure'.

Translation caused friction

What is interesting about involving patients in this PROM activity is their reactions and responses. It was if they were validating the survey responses to their own **Experience 1** and it caused friction. For example, when discussing how MS affected their ability to tie shoelaces Participant 5 stated, 'Laces, laces. In the morning I can do them up but after lunch I need my mum'. Participant 4 shared that he opted to wear Velcro shoes: 'Aren't you better buying the shoes with the Velcro? I've had the same shoes, the same type of shoe for 10 years. Don't walk anymore, don't wear them out and so much more convenient'. Participant 5 explains that he liked his trainers and did not want Velcro, which Participant 4 could not understand. Their experiences did not match, and this caused friction between the coherent stories and messy practices of everyday life.

When the information was being collated on the visual displays with categories and dots, the participants began to show reactions of surprise and almost disbelief at some of the results. Even though they had been part of the generation and collection of them,

visualised in this way, they did not match their own **Experience 1**. Here, the discussion data is combined through the collation of their categorised external factors. This is a key step in PROM development where messy contextual information is formatted to produce **Experience 2** data. This activity positioned the participants as spectators (or an audience) to the reduction process. When they were not participating any more and their experience become redundant, part of the information was left out of the new version being created in front of them. This is shown in a comment from a participant: 'It's like your Carol Vordamin on countdown'.

This comment was followed by laughter from the group of participants. There was laughter at different points through the discussions, highlighting feelings of nerves, jokes or tensions. However, this specific moment of laughter is interesting and I think worth analysis, due to the activity we were engaged in. It is important to pay attention to the interruption and response in the visualisation activity as an opportunity to generate sensitivities and questions about the activity rather than ignore it. As a design researcher, this was a disconcerting moment where I feared I was excluding the participants and became part of the translation process. Likening me to a TV host within a joke is an interesting response to the activity. Laughter is a situated activity that is part of the communication between the people involved and has been discussed in the ethnomethodology literature (Jefferson, 1979). This is interesting for a number of reasons. The moment of laughter could indicate how ridiculous and strange the participants find the idea that you reduce accounts of life into dots on paper. Alternatively, it could be a sign that they are nervous in that they are now not in control of their contributions. If thought about through the role of the idiot here, laughter 'slows us down to resist the consensual way in which the situation is presented' (Stengers, 2005, p. 994–995). Only by slowing down can I challenge the taken-for-granted-ness of what should be taken seriously. This use of humour stops to check if we really know what is going on here. Is experience really being captured? This is an important moment as it shows that focussing not on coherent moments where subjective accounts are shared but on messy practices can activate their potential for generative critique.

This activity demonstrates how making **Experience 2** visible and tangible is a disembodying process. The purpose of creating the visualisations is to remove the mess of the working, the individual bodies and the outliers, and objectifying the information. This is exactly what scientific knowledge and processes do when they objectify the body in making it visible in these formats (Callon and Rabeharisoa, 2004, p. 28) and making data comparable for populations of people. At this point, the information becomes unhelpful for patients to use in their everyday situations, for the here, and now to complete the necessary tasks to exist. It also alienates them so that they do not recognise their own practices in

the data. This suggests that data visualisations are useful for medicine, but not often for patients.

This also raises questions about the relations between **Experience 3**, **Experience 4** and recording tools. Patient experience is done in different ways and in different contexts, and depends on everything and everyone necessary to it to be active. The previous section has shown how you cannot consider an object independently of the ensemble; so again I follow scholars of ANT who pay attention to the richness of settings, which is a common trait of ANT research (Star, 1990; Singleton and Michael, 1993; Mol and Law, 2004). These visualisations exclude the patients and their bodies, and this is why patients cannot relate to them as versions of their experience and result in this reaction from the group. As a technology of experience, the production of visual representations is key to its ability to circulate. The removal of bodies enables these visualisations to happen. In contrast to this, these visualisations could not travel to patients homes, whereas the button technique could.

This becomes a crucial turning point in working with patient experience as I'm now treating it as **Experience 4** rather than **Experience 2** – deciding not to reduce it, clean it up or marginalise the tinkering going on (Mol, 2006). Ultimately, this limits the possibility for it to travel to create a population metric scale, but in doing this, ensures that specific versions of people are included. As demonstrated in the previous chapter with the olive oil bottle being included in a consultation, healthcare professionals and patients are already working together to calibrate alternative versions of experience, and Mol argues that we should be strengthening these practices (Mol, 2006).

What I have learned in developing a new technology of experience?

- MS ensembles are critical to people living with their MS and includes much of the stuff that is left out of the medical PROM development process.
- At the moment, understandings of working with patient experience are too general and formal, and they don't account for plural settings with a range of diversity within them. These meetings have shown how what happens in a hospital is different to what happens in the home.
- By foregrounding practicalities and materialities of patient experience, I can take account of the heterogeneous actors involved, and their non-coherent accounts, in contributing to what is done in practices through specific conditions. This is a new approach to working with patient experience that values practice, the everyday and the mundane. It does not value scale over specifics.
- Material objects and tactics are part of these ensembles performing experience.

- The problem with using objects to somehow capture or measure experiences (considered as **Experience 2**) is that they are deeply embedded in their situations / ensembles.

A turning point – what does a new technology of experience look like?

When I designed the MOT study, I set out to make, or at least be able to initiate the creation of, a new PROM for people with MS through design-led research. But through the investigation and development of the different theoretical versions of patient experience and observations of practice from the pilot studies, I have come to the point where I have realised that this is, in fact, impossible. I am unable to make a PROM from what I have found because these things do not travel and they cannot scale. What is needed is an experience technology that could simultaneously capture experience ensembles, respecting their situated nature and also be scalable. That really calls for a new kind of technology of experience. And so, the question then becomes, what does a technology of experience look like that does not reduce, clean or marginalise particularities?

From the trajectory that I have taken in this thesis, I do not think it is enough to leave it at this point as the discussions in this chapter have fundamentally challenged the idea of capturing patient experience (**Experience 1** and **Experience 2**) when framed from healthcare and medical perspectives. I have alluded to inviting another perspective or purpose. In the context of delivering quality care, Mol (2006) has shown that it is a problem to assume one gold standard for all if health is at stake. If I apply the purpose of PROMs to my new thinking about patient experience, then it seems silly to only have one format to produce technologies of experience. We need multiple, and I now want to know what this might look like. Therefore, it is clear to me that the next thing to do would be to briefly present two possibilities to take this proposal of a new technology of experience forward.

Proposal 1 – Individualised experience technologies built around a patient's own ensembles

The first proposal is around the existing practices of people's daily life, such as the yoghurt pot test mentioned in the MOT meeting, which are not scalable. This proposal suggests working with MS experience ensembles before they have been cleaned up. It aims to take the mundane, everyday activities that people with MS find important, seriously. Developing this as a proposal would involve going to people's homes to uncover practices of measurement embedded within the situated actions and activities that are personal and meaningful to them. If this activity then became the technology of experience for that individual person, then it could be used in conversations with their neurologist or nurse to talk about change, subtleties and progress of their condition within the context of their life. This is an individualised PROM for situated, individual people. As it is for this one person, it does not need to travel. Therefore, it could become even more specific within their lives based on

how they are affected by external factors. To develop these patient-embodied measures, I propose an ethnography or participatory form of research within the homes of people with MS willing to participate to discover the situated actions that are used as ways of measuring their experience.

The challenges of this proposal for medicine are that it would require individualised care, letting go of scale and comparability. Nevertheless, it would allow the patient to measure and articulate their experiences in ways that are relevant to them, and the only way of doing this is through the actions the patients have, not through statistics or psychometric calculations. I can imagine this could be of value to patients with progressive MS who are likely to have co-morbidities (i.e., multiple health concerns and illnesses) and are patients with complex medical needs (MacLurg et al., 2005). This proposal would address the limitation that current PROMs perform patient experience at a population level at the expense of those patients being able to recognise themselves in the results (as demonstrated in the MOT study). Patients would be able to identify themselves in the data generated. This would lead to further questions such as, what could a homegrown technology of experience tell us about accountability practices for people with MS, and for generating knowledge outside of clinics and labs?

As an **Experience 4** based proposal, it recognises ensembles including people, objects and activities rather than the phenomenological version of **Experience 1**. Therefore, it does not do what existing technologies of experience do. By staying situated in everyday actions involving the specificities and complexities of individual people's lives, it can not be part of population data as it stays completely individual. **Experience 4** is not applicable to others and not transportable. This proposal intentionally sacrifices scalability by creating a really situated personal measurement of home based ensembles. This is a trade-off between engaging with the very situated worlds, actions and meaningful activities of patients' lives and the need to be transportable, which is currently not explored in outcome measurement research and development.

I argue that this proposal has agency in other ways. In relation to how this proposal works with different versions of **Experience**, this approach could actually compliment transportable versions or forms of **Experience 2** e.g., the clinical data, the visualisations and graphs, produced in routine clinical care. The proposal reveals and works with things left out by medicine and follows Stenger's reclaiming of mess to deal with what escapes objective categories. It operates differently to clinical technologies of experience as the patient, rather than the clinician, researcher or designer, works with the demands on material practices to produce experience. In other words, it stays with a person's subjective experience, embodied perspective and ontological view as they validate experience for themselves, through their interactions within specific activities. As a technology of experience, it includes and

celebrates the materiality of subjectivities that are central to impacting on people's everyday lives through how they work, care for themselves and their families.

This would enable **Experience 4** to become a clinical tool that could be useful to further illustrate specific and complex aspects of people's lives, that current tools struggle to access. This proposal provides a way to contribute knowledge to crucial clinical conversations such as what is improvement or deterioration in everyday situations providing information that might not be picked up by clinical tools. For example, the pilot studies highlighted a tension in how measurement outcomes, such as walking distance measures and the PiP criteria, are set up to include and consider only certain things as valid and fail to shift during the course of an illness. This proposal would be sensitive to subtle changes for individual people, such as being able to eat a yoghurt better than the day before, having better control of the paintbrush, or being able to do up more buttons in the evening. Ultimately, it centres on activities that people actually care about e.g., controlling a paintbrush won't matter to everybody, but it will matter a great deal to some.

If these two versions (**Experience 4** and **Experience 2**) could hang together, co-become, or collaborate in this way it would be quite radical as it would recognise the everyday practices of (non-clinical) people could supplement and work with the cleaned up practices of medicine. This has the potential to contribute to wider discussions about trial or treatment endpoints of improvement and how these are determined for different people living with MS. What this also does is work towards creating versions of experience that count for patients in their everyday lives, not just the original intensions of PROMs for medical accountabilities and resource management – which has been a key question raised throughout this thesis.

Proposal 2 – Under and Over

The second proposal is to design a task that could become part of everyday life for more than one person. This is actually an approach that I am starting to work on outside of this thesis in my work with the Barts MS research team and collaborators The Agency of Design. In September 2018, we launched *Under and Over*, a hand-and-arm activity pack that comes with a plastic grid, two shoe laces and a pattern book (shown in Figure 50 and Figure 51). The grid has been designed for people with MS whose hand and arm function is affected by their MS. They can thread the grid with the laces, creating an endless variety of different patterns and designs. The book that comes with the grid proposes a range of designs, from simple patterns to complex imagery. Initial design development with five people with MS has been conducted and it has been exhibited at the ECTRIMS conference in October 2018 (Figure 52 and Figure 53), where the response has been very positive. One participant we tested it with had significant hand-function impairment and physically struggled to complete the simplest pattern. However, the participant found this challenge motivating,

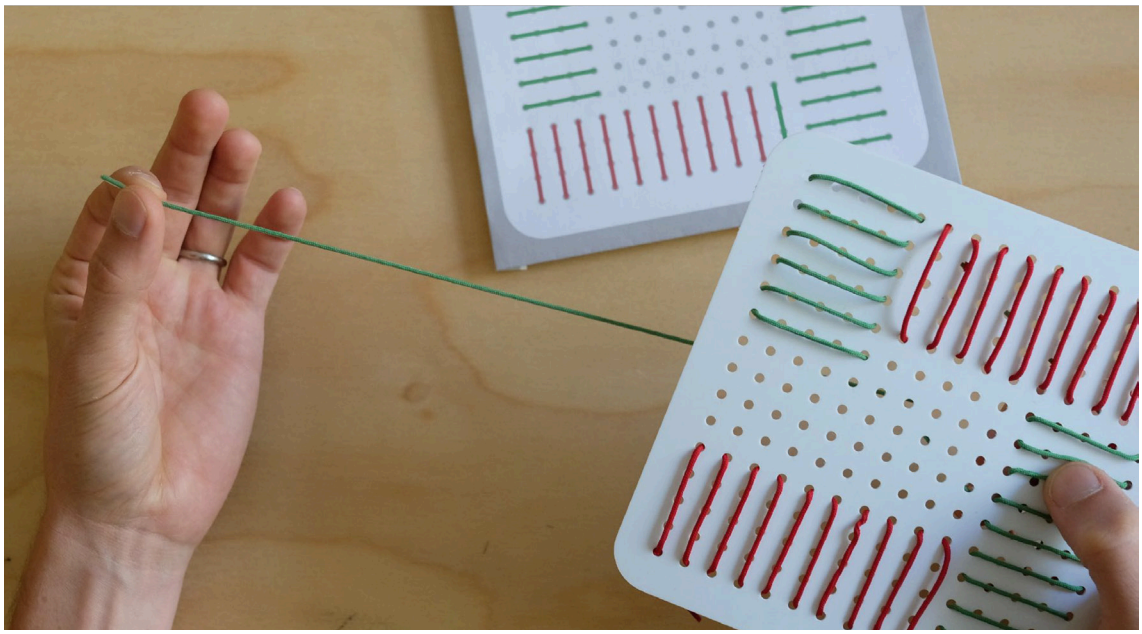


Figure 50 *Under and Over* grid.

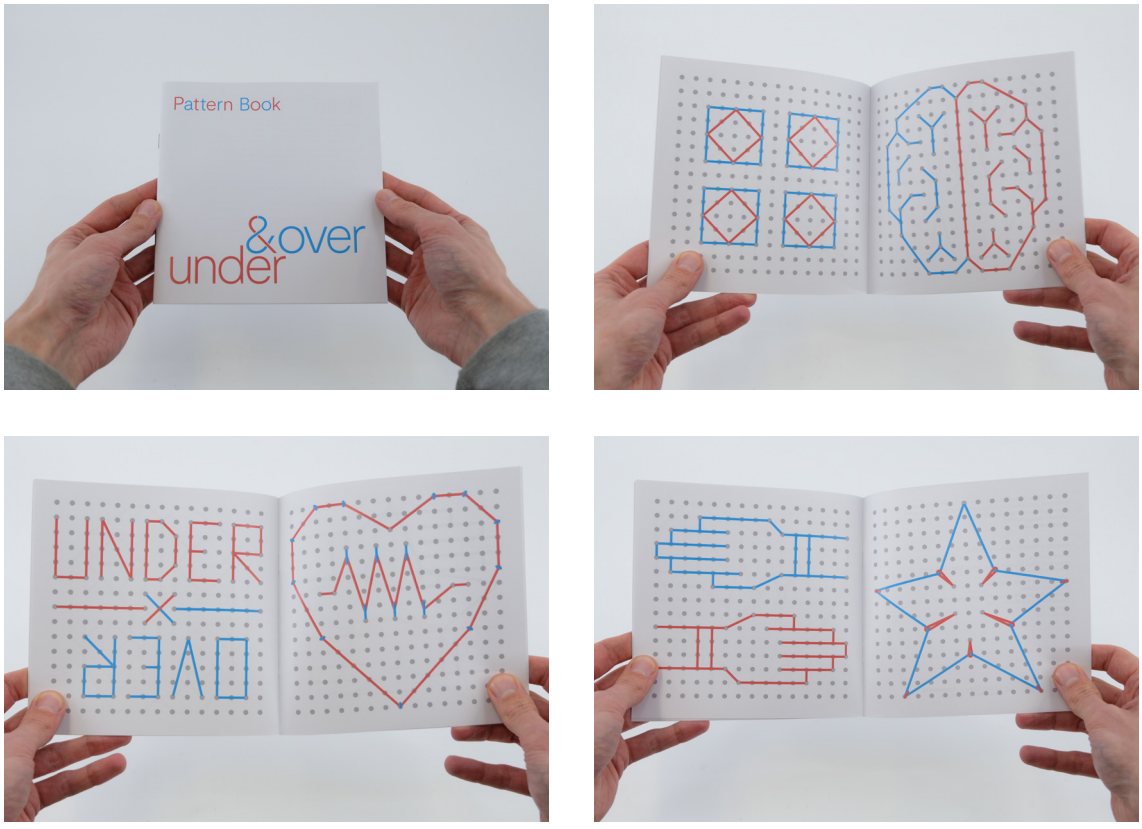


Figure 51 *Under and Over* pattern book.

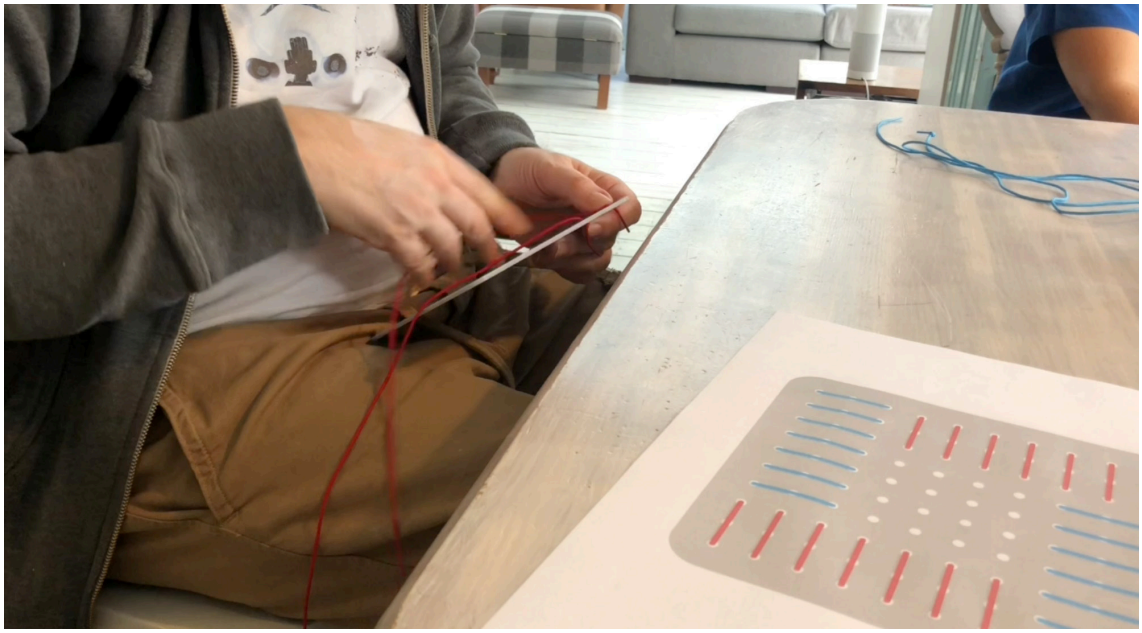


Figure 52 Developing the activity with a person with MS with upper-limb disability in their homes as part of patient design activity.

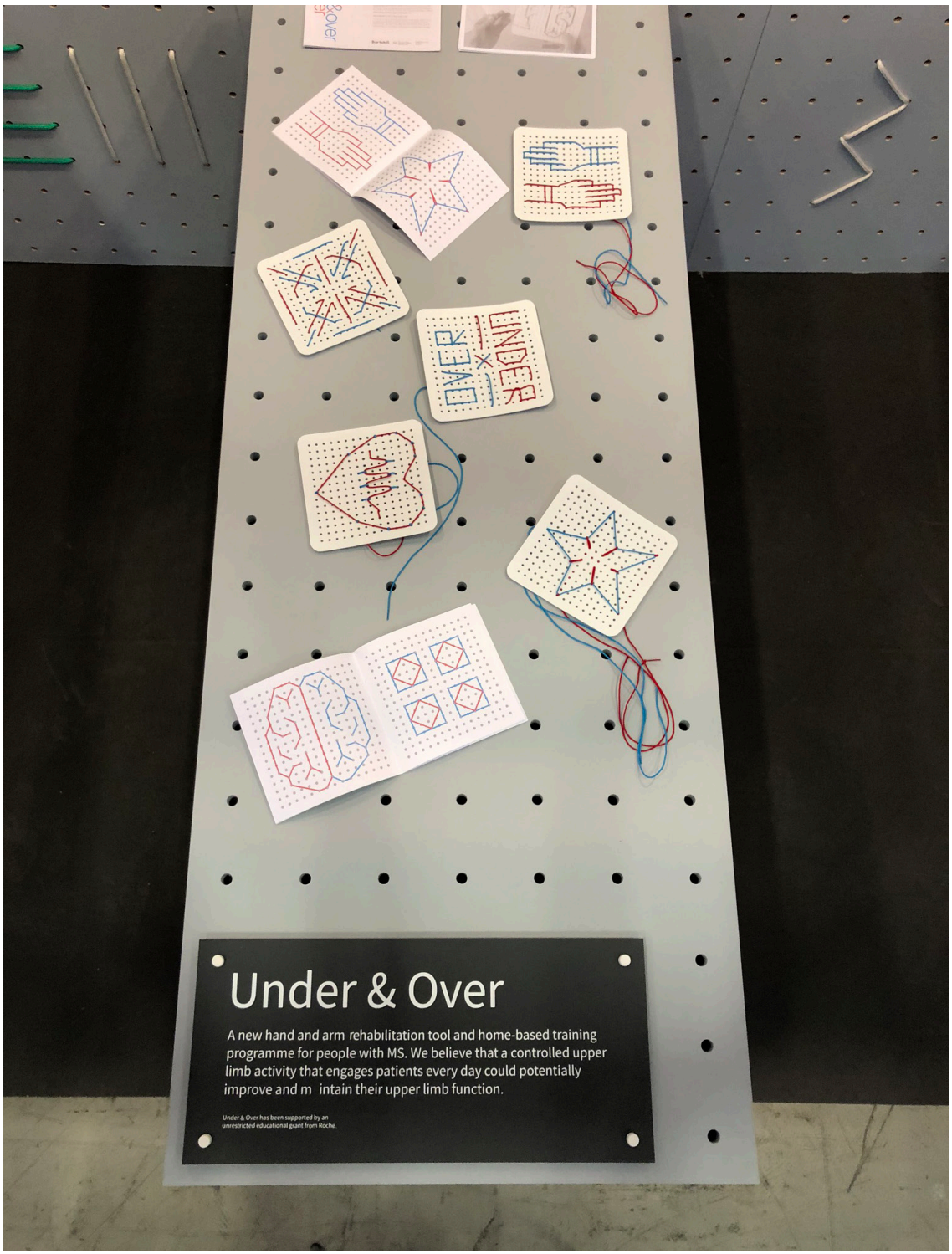


Figure 53 *Under and Over* was exhibited at the ECTRIMS conference in October 2018 in Berlin (Photo credit: The Agency of Design).

allowing them to compete against their own ability. As such, ultimately it was rewarding and enjoyable.

So this proposal provides a group of people with a standardised activity but at the same time, also allows a large amount of individualisation, as they can make it part of their everyday lives in different ways. The tool is flexible enough that people can create their own patterns or complete pre-designed patterns in any way they like, and conduct the activity where and when they like. Once this has been further developed, I anticipate that what people do with the tool will be indicative of their hand and arm function; they will be able to complete more complex patterns over a longer period of time if they have more cognitive and physical function. This then opens the door to explore if this activity contributes to the rehabilitative functions for a person who completes it regularly. This is a work in progress and requires a major study involving a large group of patients to use this tool in their homes over a long period of time. Given the institutional complexities of arranging such a study, this is beyond the scope of this thesis.

This proposal seeks to explore and take seriously external factors, paying close attention to how people with MS manage to complete a standard activity in different conditions. This is done in an open way involving design without being overly scripted or dominated by being externally visualised into **Experience 2**. This avoids some of the assumptions of designs current involvement in designing patient experiences as mentioned in the literature review as a first and second generation understanding of experience design. In *Under and Over* specifically, the visualisations that patients can make work with the assumptions of materiality (where people are solely depositories of knowledge to be visualised) to establish it as an **Experience 4** tool where the artefact is the entry point into experience. Through making the patterns, they are performing their patient experience. These patterns are not pre-existing but are dependent on felicity conditions, or external factors, so are created in response to the changing MS ensemble which fluctuates and changes daily. In the pattern's creation, it brings forward MS ensembles to produce knowledge, instead of reducing it.

It is interesting to think through the implications of this proposal for how MS is practiced in clinical care and in research. As mentioned in Chapter 1 when introducing the field of MS research, the categorisations of MS are changing where the historical disease categories are being rethought and challenged to create new opportunities for the treatment, care and monitoring of people with MS. The *Under and Over* proposal supports this future outlook as it is sensitive to the changing nature of MS as a degenerative disease over time and recognises and works with the variety of external factors affecting people each day. This activity is open ended enabling people to adapt it to their lives by standardising conditions around them depending on a number of factors such as how they feel, their upper limb

ability, if they're being watched, the weather etc. In a very subtle way, it can be used as an indicator or test of upper limb function for people that use it.

I imagine three different ways this standardised design tool could be used in practice which would have productive implications for my different understandings of experience. Firstly, giving this standardised object to a variety of people in a variety of ensembles, could go onto create controlled **Experience 2** visualisations by removing the openness of the tool and administering it with specific tasks. So this would be a controlled use of the tool where some of the specificities (such as pattern choice, or activity duration) are controlled or standardised across a group of people. The completed pattern can be considered as an immutable mobile, visually representing and recording the specificities of experience for different people based in different ensembles. In doing this, the tool speaks to **Experience 2** and becomes a tool to enable patients to represent their ability at that time. Interestingly, the validity of this technology sits in the material object as it is standardised across all patients, bodies and ensembles.

Secondly, if you give it to people with MS to use at home with the pattern book they can use the tool freely and there is an openness to it. People can do whatever they like - they are in different situations, they have different interests, aesthetic preferences as well as abilities. What they will produce is totally unknown before they start the activity, and is completely dependent on the external factors of that time and space. This would produce **Experience 4** however, any appearance of **Experience 2** might be misleading. In this example, **Experience 4** becomes positioned arguably closer to experience, or can be thought of as a fuller way of talking about experience by incorporating different versions, as the MS ensemble has more freedom over what is produced making it an entry point to think about experience.

Thirdly, there is an option where the tool could work between these two previous examples. So even when someone might produce the same pattern as someone else, they could be produced in different ways. For example, one person would complete the pattern over three days and another person in one hour. Here, they could be producing data for **Experience 2** in ways that don't imply the constraints of a cleaned up **Experience 2** process.

These three scenarios illustrate how the tool spans a range from **Experience 2** to **Experience 4** depending on how it is used. This means that the same tool can service multiple forms of experience as it moves fluidly between recognising **Experience 4** and being allowed to be used for **Experience 2**. This shows how the different versions of experience are not competing, but provide lenses on the same experience.

Discussing the two proposals in this section of the thesis has brought me to the point where I am starting to develop a narrative about how these tools might work based on my understandings of a new technology of experience. The implications of this impacts on my understanding of the different versions of experience and this productively starts to suggest how the separation of these versions in the experience table might not be as clean cut as it

might originally suggest. For example, this initial discussion has demonstrated how they can be used as different lenses to view what is going on in different practices of patient experience.

Limitations of proposals

These two proposals outline practical and theoretical directions to which the research of this PhD has led me. It is important that I describe the limitations as to why I am unable at this point to take either of these directions further within this PhD. The practical contingencies of working in a practice led way with patients within the NHS demands a significant amount of time and preparation. I have illustrated the ethics process with timelines involved for the MOT study (see Figure 10 on page 32) and have included documents generated in the appendix of this thesis to demonstrate the demands involved in this work. For me to conduct either approach with people with MS would involve another research study, involving protocol design and development and seek ethical and HRA approval.[11] These activities are beyond the scope of this PhD. I understand that it is a shortcoming that I cannot present the results of this work here. Nevertheless, I describe these promising research directions as they are the direct results of, and evidence for the success of, the research reported in this thesis.

Completing the table of experience

I now refer to the table of experience developed in the literature review to complete, albeit tentatively, the final two boxes at the bottom right of the table shown in Figure 54. The reframing of **Experience 4** aims to contribute to a better understanding of the requirements of a new approach to working with experience in light of the assumptions raised in previous versions. This describes the positioning and properties of **Experience 4** as being distributed and embedded within experience ensembles. These ensembles show how action is distributed across human and non-human networks where everything must work meticulously together just to perform everyday tasks. These are not pre-existing and are totally dependent on external factors including specific differences in environments, bodies, objects etc. Assumptions in this version include how everything can be performative and be able to change in moments of coming together. This accounts for how **Experience 4** includes much of the stuff, or mess, that is left out of the medical PROM development process and includes it as experience phenomena. By involving design to work with **Experience 4** it can foreground practicalities and materialities so objects can capture and measure experiences if they are deeply embedded in their situation or ensembles. But the limit to this is that they can not also be scalable nor generate simulations of experience. In order to work in this way

11 I am currently developing a protocol for *Under and Over* to allow me to test it in people with MS's homes. It is planned to submit for ethical review later in 2019.

	Description	Assumptions	Design approach
Experience 1	This first understanding of experience is of a patient's inner, subjective experience of events that has happened to them. This understanding is heavily influenced by phenomenology and is dominant in healthcare practices that threat patients as subjective beings.	The limitation of perception where individual people view the world differently depending on their embodied perspective and ontological view. This also presumes that humans know their own minds and access their thoughts, i.e. their memories. STS would argue that this point of view prioritises humans as perceiving subjects above all others.	A first generation of experience design understands customers as being passive recipients of experiences that designers can create. A second-generation understanding likens experience design with co-creation and participatory design tradition where users are involved to talk for themselves and contribute to the change process. This understanding has underlying motivations of democratic principles of work management dynamics.
Experience 2	This version takes patient experience as a measured and objective phenomenon such as a number or a measure produced through data as generated from and reported through patients' subjective accounts. This version can travel and have agency in making subjects. This is not to be confused with the phenomenological perspective of experience, which is the 'inner experience' of a person, this notion is a generalised data version.	Presumes people are reflexive, rationale actors. If you fail to produce data, you do not have an experience. People are a repository of knowledge that need to be quizzed. Raises questions about the different forms of knowledge left out by methods to capture or represent this information.	Typical design inscription (immutable mobiles) that visually reduces knowledge production to simple and interrelated shapes. Action is ascribed to these shapes that are at the center of design activities.
Experience 3	This third understanding emerges out of the situated interplays between people, measuring instruments, etc. which are socio-materially mediated. It argues that 'experience' is the result of these practices and so cannot exist without them and has agency that can cause other actants to act and produce subjects. It is constituted in relation to various elements, and there is no single central core. There is an indexicality of this experience where it is dependent on where it is embedded.	This version rejects the object/subject divide, but as a performative understanding, it has been used to focus on language, presupposes a backstage where there is a consciousness and is limited to recognising performativity as producing visible effects.	An understanding of the design process as entirely performative where both subjectivities and bodies are performed. Socio-material assemblies of patients, measurement tools, health professionals, spreadsheets, etc. are performed that achieve different experiences. Can be simulated through experience prototypes and design tools.
Experience 4	This is a distributed experience that has distributed agency. It is not pre-existing and can have no visible effects. It is dependent on external factors. This understanding of experience is influenced by the notion of event to consider the situated action of this model of experience brought forward through MS ensembles.	Everything is performative and changed in the moments of coming together. Everything has the capacity and potential to become an experience phenomena – not limited to medical or scientific objects. It is not scalable and cannot be simulated.	Can work with experience through artefacts as entry points. Works with mess through practice. Can be inventive and speculative in that it is unknown before the event. By slowing down can let other things come forward that would have been othered.

Figure 54 Completed table of experience.

through design, it is necessary to slow down to let other things come forward, that would have otherwise been othered.

In a way, the proposals presented in this chapter problematise the presentation of these categories of experience that I set out in the experience table in that they appear separate from one another and appear to sit in contrast. Thinking through these proposals actually suggests that the different categories might influence, or serve each other, working as different lenses to view and understand the same experience. These versions of experience are not different experiences, they are different lenses on the same experience. In the conclusion I reflect on the table of experience as a contribution of the thesis along with further implications and limitations of this work.

Conclusion

This chapter has described the MOT study, which emulated the tactics of producing a PROM. It did this by bringing together people with MS whose upper limb function is affected by their MS to discuss activities they do every day. Through comparing these with others' experiences and interrogating the specificities of these situations, things came up like aspects they have difficulty with, personal preferences and external factors. This was interesting, as I found that introducing substitute objects to the discussions were unusually unlike the situated experiences of their homes. It further highlighted points about the limited performative effects of visualisations of experience data and the potential for MS ensembles to travel and scale.

This study has challenged the ability of a PROM development process to represent the world out there to involve actual patients and actual practices. Slowing down patient experience has enabled me to unpack the motivations and requirements of generating experience for research and medical purposes. This then suggests that there is a world of experiences and other technologies that is jeopardised by the practices and existence of current PROM tools and approaches.

This chapter, in the description of the MOT study, has opened the door for the need for a radically new way to do patient experience – one that privileges the ensemble over scalability. I have concluded this chapter by pointing to two different directions as future possibilities to continue to build on the work presented in this thesis and to propose the next steps of how they might operate.

From the discussions in this chapter, I have completed the table of experience developed throughout this thesis while also starting to explore how these different understandings might be brought together, or could work together in different ways in clinical practice and care. This is an incredibly interesting proposition and point for further research.

Chapter 6: Conclusion

In this final concluding chapter, I revisit the main arguments of the thesis to draw out the contributions of knowledge to the fields of healthcare, social science and design research. I will also use this chapter to address and answer some of the practical and theoretical questions that I have raised throughout the thesis.

This thesis has identified different ways that patient experience is enacted in the NHS for people with MS in an environment with multiple pressures from government policy, quality standards, commissioning and measurement outcomes. This leads to a number of specific versions and practices of working with patient experience from different fields that carry with them a variety of assumptions, procedures and tensions. I referred to these as different versions of experience and present them as a table of experience in the table in Figure 54. I use this table to firstly identify areas to contribute conceptual understandings of the notion of patient experience, then again at the end of the thesis to position my new discoveries. Methodologically, this thesis has investigated the conditions, procedures and instruments for producing these versions by opening up existing technologies of experience.

The methodological rationale for this thesis is built on ANT approaches and performativity literature, which considers knowledge not to be pre-existing, fixed or stable, so that any object of study is brought into being through specific situations, interactions, objects and humans involved in them. Therefore, this practice-based design research approach has shown how practical interventions can be deployed in specific situations to enable alternative versions of experience to come forward. In doing this, design research slows down existing technologies of experience to see how certain things are left out, are made transferable and can be made valid. The discussion and analysis from the practice and theoretical discussion, in light of the resulting interactions from the pilot studies, affected the trajectory of the final piece of research and my original intensions to make a new PROM. As it became clear in the analysis and discussion in Chapter 5, I cannot make a PROM based on individual ensembles because respecting them means sacrificing scalability and transferability. These, however, can be worked with if considered appropriately. Therefore, at the end of Chapter 5, I point to two directions as future possibilities for a new technology of experience around **Experience 4**, involving the development of individual embodied experience measures based on individuals' activities and the design turn of introducing a physical artefact that could become part of people's lives. These directions as future research work will take years to unfold, given the practicalities of working with design-led research in the context of the NHS.

This thesis contributes to knowledge in three main areas. Firstly, it contributes to understandings of the notion of patient experience as it has identified and articulated a range of versions of experience in theory and practice. Secondly, this thesis reports on and provides analysis of design-led research within a complex and challenging health care environment involving patients, healthcare professionals and medical researchers to explore different versions of experience. Thirdly, it has uncovered situated actions of people whose

MS is affected by their upper limb function and the work involved in everyday practices of maintenance, measurement and care. I will now go into each contribution in more detail.

A contribution to understandings of the notion of patient experience

This research was initiated from pressing concerns that emerged from my previous practice when I was asked to "improve the patient experience for people with MS through design." This first engagement with patient experience as a concept, was as something to improve through my involvement as a designer working in an interdisciplinary landscape. By unpacking the assumptions and claims in this statement, mainly that patient experience can be known, that it can be improved, and importantly, that design can be involved in this, my understanding of this concept has radically changed. I trace this exploration through the construction of the table of experience which is a key infrastructure of the thesis that I now return to and reflect on as an important contribution.

The work in this thesis has demonstrated that patient experience is not a topic of research restricted to healthcare, medicine nor design, but involves interconnected fields and practices. The table articulates nuances between these contrasting fields, where patients are positioned differently and are beyond being predictable generators of data, or resources to be accessed. It has become a resource that situates and juxtaposes a number of contrasting understandings next to each other in an accessible way. As patient experience is a timely, complex and multifaceted object of study, the table initiates a vocabulary to tease out different characteristics useful to multidisciplinary work. This will support interdisciplinary conversations between teams of designers interested in healthcare projects or healthcare researchers interested in design methods to understand the principles within different methods and approaches of engagement and involvement when working with patient experience.

Having summarized the strengths of the table, it is also important to consider the limitations, weaknesses or unresolved aspects of this model of patient experience. Reflecting on these also help to point me towards ways in which this research can be further developed. In the presentation of these different versions of experience, I am mindful of the cleaning up process that scientific facts go through and do not forget that design leaves stuff out too. This table has been constructed from my empirical work based in one specific chronic condition, within a clinical academic research groups in east London through my practice of relatively unconventional interaction design. A point of interest, or future work, would be the investigation of this table either across another chronic condition or through other forms of practice. The nature of the table and the different understandings of experience being transportable to other conditions or areas of health research is an interesting and important consideration. It would be interesting to consider how the approaches and assumptions behind **Experience 1** and **Experience 2** would seem to travel between different situations e.g., for a cancer or diabetes patient opposed to someone living with a degenerative neurological

disease, or whether **Experience 2** would operate in the same way in a rural hospital in the Outer Hebrides as our centre in East London.

In response to the practice-based elements of the work, I am frequently asked if my existing practice-based work would 'work' with other conditions so for example if *Digesting Science* could be used with children suffering from asthma, or cancer and not just children affected by MS. I am reluctant to speculate as to the efficacy of transporting the pilot studies or either proposal to another condition or context, but transporting the tasks, tools and design process used to produce them could provide further interesting work. The methodology of inventive methods and pilot studies can be explored elsewhere but applying the finished practice feels like a discounted form of research, and design. Although this non-transferability could be considered a limitation of the work, pulling out and articulating different definitions and assumptions has demonstrated the richness of paying attention to sensitivities to specific settings of research that we are always already involved in. For example, the situatedness of scientists communicating at the ECTRIMS conference, or people with MS having their walking measured uncovered particular insights to this setting. This follows what Puig de la Bellacasa (2017) frames in *Matters of Care* as the possibilities and obligations of being involved in more than human worlds. This puts forward ways to start to care again for patient experience through situated practices of research. This involves taking into account others who have cared for it, for example through different research disciplines understanding of experience. So instead, what I hope that this thesis has demonstrated through the building of this table is the importance that the question of how to do patient experience needs to be posed and reposed for different bodies, illnesses and spaces by different researchers and practitioners.

The task of this research is not only to identify how patient experience is currently done, but also how it can be undone, and re-done through the creation of different versions and technologies of experience. This is relevant to designers, design researchers, health researchers and clinicians working with patient experience as a subject, topic, or as material to highlight that patient experience is something that is made, and continually re-made in the everyday practices between patient bodies, tools, environments, objects, and people. By consciously addressing this topic through research and practice, there is a danger of enacting our own assumptions and those from our field when engaging patients in research. Therefore, the purpose of the work in this thesis is to illustrate that we are also in position to do it differently, as this research is concerned with producing knowledge that can inform others to work differently when working with patient experience. The reframing of **Experience 4** at the end of Chapter 5 supports this and aims to contribute to a better understanding of the requirements of a new approach to working with experience.

As is frequently the case in healthcare research and service improvement projects, there is a requirement to involve patients directly in the process. This thesis has shown how to work with an expanded notion of patient experience to contribute to these practices by

acknowledging the variety of differences in people and not reducing or constructing them as vulnerable subjects, nor responding to a need to empower them through solutions.[1] By paying attention to people and their capacity to participate through different methods enables different possibilities to come forward. This is a move away from working with patients in forms that are already constructed, to different understandings where they can be actors in ensembles - a network of different entities working together - that have the ability to say, think and act in the way they want. This is relevant to those concerned with involving people in either a research, design, or service development process, such as PPI practices, EBCD work (Donetto et al., 2015) or experience prototyping (Buchenau and Suri, 2000), where practitioners are responsible for enabling the articulation of patient contributions and relevant sensitivities to conduct this work. Hopefully, the contributions of this thesis can suggest how to address some of the barriers and challenges in the complex institutional processes ingrained in the settings of this work, where, for example, ethical approval or guidelines does not guarantee that you are prepared for the ethical dilemmas that you may be confronted with in practice. Thus, researchers and research participants cannot be dealt with in a single guideline. If we are to start to uncover the messiness of patient experience work, and relations within the richness of settings, then a more nuanced understanding of ethical principles needs to be developed. The table of experience, for example, could be a starting point in practice-based work involving patients to articulate their roles and unique contributions to collaborative projects.

A contribution to design

This thesis suggests a new way to work with patients as MS ensembles through design. As a whole, the design interventions allowed for a better understanding of the values and processes underlining and within different understandings of patient experience. It revealed some of the requirements and considerations of working specifically with the ensembles of a degenerative, chronic illness, opposed to the experiences of users or consumers. In contrast to medical or scientific research approaches, this design led process of inquiry engaged MS ensembles involving people with MS, their carers, technology, objects and tools to bring forward new insights and issues relevant to this specific group. From the results of this work, I now suggest that design needs to consider slowing down (Stengers, 2018) in order to be sensitive to external factors and account for specific versions that are an upshot of existing measurement and representational devices. This is a key argument of this thesis and

1 Arguably, Callon (1986) argues that this is working against empowerment, as to speak for others is to silence them.

suggests opportunities for further intervention within this context to better understand the different values and processes underlining different practices of MS.

One of the questions discussed in this thesis has been, what counts as experience, and for whom? This is still an important question to take forward by designers interested in this area. I imagine this will contribute to a discussion about how designers working in healthcare specifically consider patient experience, both practically and theoretically, with influence on their own reflective positions. Here, this would be a consideration beyond what designers can see and anticipate, including the representations and reduction of patients in visualisation and workshopping activities or the potential assumptions that design tools may carry within them. This particularly sets a challenge for designers to encourage participation without limiting activities to physical interactions, but to engage ensembles in design activities. In doing so, this recognises the limitations to participation and acknowledges the capabilities of humans to take part, along with the potential for non-humans. Thus, this calls for creating spaces and approaches where things can come forward and invites a new consideration of what designers think they are making or doing (Michael, 2011). It could also further support designers to be critical of how design is possibly being enrolled or involved in service improvement projects and the assumptions that others have of designs' role.

For this research process, the idiosyncrasies of the pilot studies and being able to respond to what I was experiencing was crucial to developing both the MOT study and constructing insights on ways of working with experience that had an important influence on shaping the thesis. This thesis sets out to research patient experience and then create a PROM. Through the course and trajectory of the combination of the theoretical and empirical research process, it turns out that in actual fact, creating a new PROM is not the correct thing to do. Re-positioning the research to respond to these insights enables this work to become a form of brief or requirements, or a starting point for other's research to create a new form of experience. Or to continue my own. This decision steers me clear of being pressured into creating an intervention that runs the risk of assuming pre-made experiences. By not presenting a concrete solution to patient experience but demonstrating how to re-configure the problem, or the starting point and technologies for those practices, I turn patient experience from matters of fact to matters of concern (Latour, 2004).[2] If thought about as a matter of concern, this then offers new possibilities for conceptualising patient experience in alternative ways compared to how it has currently been positioned i.e. as a pre-existing resource to be measured, acted upon and improved. This then contributes towards building a critical approach to patient experience work with a sensitivity for the implications of individuals involved in this work. For example, my proposal for a

2 As matters of concern, patient experience can be thought about as open to critique where the different ways it is gathered and assembled can be interrogated.

performative understanding of experience emphasises the practices of patients as well as researchers and clinicians as concrete material actions that produce knowledge. By researching the performativity of patient experience in the making of research events, new compositions of the topic of study have been produced. This is a benefit of slowing down the design involvement in patient experience, as it opens up new ways of thinking about current problems and how they are presented, to thinking about what design can bring forward, as well as who else design can speak to.

On reflection, I possibly could have anticipated that by not choosing traditional methods of research – interviews, observations, and questionnaires, but to critique them for enacting coherent accounts and employing inventive methods, would not enable me to create a PROM on their terms. My argument is that by using scientific or medical research methods to investigate patient experience would cause the subtleties, frictions, and mess of practices of patient experience to be overlooked. This has productively been described as 'undoing methodological hierarchies through care' (Jerak-Zuiderent, 2015, p. 903), where the hierarchal order of different empirics – ways of producing knowledge - is removed to value practice-based knowledge. By having a sensibility or attending to the research topics as 'matters of care,' has enabled me to stay with the process of new understandings of experience in the process of becoming. By keeping close to the frictions, mess and complexities of what happened in practice enabled me to uncover where and how to study these new versions. This helps to avoid the 'god trick' (Haraway, 1988) of researching from nowhere and instead, enabled me to stay situated. For me, this is an incredibly valuable lesson that the PhD has taught me.

Another important point to reflect on in concluding the arguments of this thesis is my position in relation to feminist technoscience and how the work of this thesis engages with this field. Feminist technoscience is a field of work that I did not intentionally address in the outset of this research, hence the lack of direct reference to it in the early chapters of the thesis, but one that I naturally stumbled across both in theory and practice. Looking back now, as I was trying to find my way through notions of patient experience within the literature, authors such as Annemarie Mol, Susan Leigh Star, Vicky Singleton, Donna Haraway and particularly Jeannette Pols have guided me through both the empirical and theoretical work. From examples of practice, my colleague from PhD By Design, Bianca Elzenbaumer and other feminist design researchers including, Sarah Pennington, Ramia Mazé, Kristina Lindström and Åsa Stahl demonstrated how to account for and think through my embodied position as a researcher embedded in an empirical context, with an emergent topic of study.

I can now trace how these influences have guided the investigation and discussion in the thesis, in particular in the ways I have taken up the notions of slowing down and paying attention as interesting ways to think through exactly what happens in moments when patient experience is brought into being and circulated. These concepts build on established

feminist modes of observing and doing technoscience in a situated manner which enabled me to think through my practice and deny any form of reliance on unmovable assumptions. This gave me the confidence to involve my own subjectivity and remove the distance which might have created safe and disembodied analysis or design proposals. Within the practice, it encouraged me to have confidence to slow down and stay with the specific of what I was uncovering with the patients I was working with. It encouraged me to pay attention, and take the yoghurt pot or paint brush example seriously. I see this call for slowing down design research as an empirical approach to dealing with the mess uncovered and brought forward through design encounters within design-led research. These concepts have come to show me the importance of my voice, my design insights, and my approach to engaging in new and different contexts as a design researcher. These sensibilities provide me with skills for not just my future research endeavours, but for how I navigate academia and the institution in the next stages of my career as I continue on my academic journey.

I come back to this balance of working as a designer within healthcare, where the demand (onus) is to constantly do good and improve people's lives, productivity, reduce error, etc. Thus, almost resisting this, in the name of research, is to seek out what is arguably equally as important and takes time to slow down and study properly. This contributes towards design research being understood through its own terms rather than through the lens of the dominant positivist approaches of science and medicine, which is the historic effort of the field of design research (Rodgers and Yee, 2016), or being pressured into commercial interests to produce solutions. This contributes to design being acknowledged as a distinct research discipline, which can contribute to better understandings of research problems from other fields, such as science and medicine. In turn this will strengthen other fields' understanding of design as more than visualisations or problem-solving practices, but as a research discipline. In light of this, I plan to disseminate the findings of this thesis directly to the design research community but also in the medical and healthcare research communities highlighting the unique contribution of practice-led design research to the topic of patient experience. These publications will contribute to the growing body of healthcare design research collaborations and contribute knowledge on the unique interdisciplinary nature of this work.

This thesis was initiated from my reflections from my long-term collaboration working as a designer within an MS research team based in at QMUL. My reflections and learnings were brought about through investigating patient experience and have enabled new directions in my design practice that I doubt would have otherwise happened. It has also enabled me to position this design practice within the context of academia in a number of fields, such as STS and healthcare research. This contributes to existing evidence around the fruitfulness of design-science collaborations and contributes to the practice of design researchers working within NHS services and healthcare research requirements. The benefit of a long-term collaboration has enabled me time to demonstrate to the MS team, the

medical school and the university (which does not have a design department) the potential of design-led research. This is another important lesson at this early stage of my academic career, as I'm aware of the national academic climate where researchers need to be able to clearly articulate and demonstrate the contributions and impact of their work. It is hoped that the completion of this thesis and future work relating to it can encourage and support more design research collaborations with academic healthcare research groups.

This prior experience with the Barts MS team along with the experience of the PhD has equipped me to work with the NHS, which I have already described as challenging. Ethical processes and obtaining permissions to conduct practice-based research takes a heavy demand on time, which is limited over the course of a PhD and is demonstrated in the number of procedural documents included in the appendix. By including these documents I hope to demonstrate how this process is far more complex (practically and conceptually) than any guidelines currently describe for designers wishing to work with patients as part of a research process (Suri and IDEO, 2015). So, I hope that this thesis can productively contribute to the growing body of literature and practice which demonstrates how practice-based design can work within the NHS research processes and procedures and not only this, but also use this as a site to be conceptually productive. For there to continue to be design research conducted in collaboration with medical researchers, in my opinion, there needs to be more work to support the HRA and NHS ethics panels to understand different research approaches and forms of knowledge, beyond the restrictive categories of qualitative or quantitative divisions.

As I conclude the work of this thesis, I am now in a position to reflect on my own personal position within the research and also the Barts MS research team that I have been embedded for so long. I am very privileged to be able to conduct research within a medical research environment and in such close proximity to biomedical researchers and clinicians who are world leading in MS. This is not to say that at times, it hasn't been a lonely pursuit, being the only designer in a medical school, but more often it has provided me with inspiration and endless insights into the fascinating world of MS. The trajectory of this PhD has opened up many possibilities to study and work with this team of health care clinicians and medical researchers beyond what I could have ever expected. As I deployed the pilot studies in the clinic, or asked researchers to take time out of their poster session to draw a plate, I was always conscious that I was asking them to do something that wasn't possibly what they would consider as research as it was not following anything like their methodologies or techniques. After much analysis over the pilot studies, I can now see that it was because of the constraints of medical research and specifically the field of Neurology, that I was inspired to respond through practice in these unconventional ways.

As I have become more accustomed to the Barts' teams' research processes, their language and formats of work over the past 8 years, it has been challenging to remain an outsider. I am now very much part of the Barts MS team. A consequence of this is that

now, perhaps, I have gone too far into the wild, I have become 'native' as I am now more comfortable with a group of neurologists than I am with designers. For this I attribute the specific qualities that I brought to the research in being able to connect with a wide range of people including consultant neurologists, nurses, people with MS and their families and engage them into different forms of design exploration. This makes the act of writing this thesis and my experience with PhD By Design even more important as it has ensured that I know how to speak back to design researchers, and those interested in leading design-led research in health contexts. This in itself is a process that has taken time to craft, but in doing so also enables me to value and reflect on the skills and assumptions inherit to design.

In saying this, I am conscious that my research process and results appear to be presented in this document as a somewhat linear narrative. This process was in fact messy, full of uncertainty and analytical iteration and the presentation of this work within this finished thesis is at risk of tidying up the mess and producing a sanitised version. I mention elsewhere in this chapter my concern that the table of experience may now come across as an essentialist reading of experience. But as a researcher, I will never forget the false starts, the uncertainties, the sketches of research ideas, the disagreements with my supervisors, the looks of puzzlement on the face of my clinical colleagues, and importantly, the sense of reward when working with different people. So I see it as a challenge for the future, to somehow stay closer to the mess, and in a way, celebrate this for what it is. One step towards this, I feel, will come from the validation and confidence that completing this thesis will provide, which builds on the support of the research communities and scholars that I have engaged with and been supported by throughout this process. I am encouraged and excited to think about how I can not only present, but also produce different versions of my research without sacrificing the mess for accountability.

A contribution to MS research and healthcare professionals

The MOT study I conducted was the first to involve patients whose upper limb function was affected by their MS in the development of a new measurement activity. The findings from this research activity suggest opportunities for intervention within the context of upper limb studies, rehabilitation and outcome measure development in order to elicit, uncover and better understand what is at stake, as well as the different priorities and concerns of the different actors involved. The study found that the current experience of trying to complete upper limb activities are dependent on a variety of external factors that are important considerations for the everyday practices of being a person with MS. Here, design-led research has provided a valuable approach to directly involve patients and their MS ensembles in the generation of this valuable information.

Specifically, for people with MS, these findings have uncovered and articulated the work that goes into completing everyday activities, and possibly, ones that would have been overlooked by medical methods of investigation. This design-led approach of

inventive methods was unpredictable and investigated patient experience in the making to demonstrate how to think with mess and deal with unusual or non-typical responses from participants. In these encounters, the design activities, tools, objects, and interactions between people and issues acted as creative explorations into emerging situations, bringing new things about, rather than returning data. In doing this, the use of design has highlighted the pre-occupations with functional aspects, validation, measurement and revealed an absence of patient input or human factors. The research has revealed new knowledge that could be valuable for considering contexts of use for outcome measures, occupational therapy and rehabilitation strategies as patients share their concerns about what is changing in their lives due to their MS. This approach has demonstrated how involving design can elicit further, deeper conversations about measurement and the role of this in people's lives and about healthcare practices in general. I hope this work can contribute to enriching the way that clinical outcomes are studied to consider what is left out. This is not suggesting that design-led approaches replace medical ways of developing outcome measures or recording experience, but hopefully, I have made the case that design approaches can strengthen and enrich these practices. This thesis has argued to not dispute the present, nor confirm it, but to add to it.

Future work

As I conclude this thesis, it is important to reflect on plans for this work beyond this thesis. I anticipate there being three kinds of future work, one conceptual, one methodological and the third practical. Conceptually, there is potential to further consider how different versions of experience work together, which has already been suggested in the proposals along with how patient experience is enacted in other spaces of MS treatment and care not considered in this thesis. Specifically, these could be MS research areas around prevention where there is an interesting role of speculation in research events. In relation to design, there are aspects around the notion of slowing down healthcare practices to investigate how patient ensembles are brought forward. This could lead to productive explorations for how design could play a role in thinking through new engagement and involvement practices.

At the beginning of this thesis I set up the notion of performativity and used this as an analytical lens throughout the research. It is a notion that has already been used in economics (MacKenzie, 2008), linguistics (Austin, 1976), gender (Butler, 1990) and healthcare (Danholt, 2005) and I now consider how my exploration of the performativity of patient experience contributes to existing understandings. The material I present articulates how performativity can be considered to enact patient experience in particular and specific ways and explores designs role in what changes, making proposals towards what can be changed. The main question around performativity is around the ongoing make up of things, such as gender. If that's the case of gender, then there are parallels in healthcare, and patient experience of a chronic disease, such as MS, is performed in everyday activities on

an ongoing basis which is not a self-contained process. In the final chapter I introduce the term ensemble, which suggests that patient experience ensembles brought forward would include gendering processes as well as lots of other processes. What I have learned through this research is that I cannot treat healthcare discreetly, I have to take these other things, such as gender, into account in experience ensembles. This thesis is limited in scope and the activities around gender in these experience ensembles could be something that I go onto look at in the future.

Finally, this practice-based research will continue through the development of the two proposals introduced in Chapter 5. Although they look like they are leading in separate directions, they are actually speaking to each other as suggested in the final discussion in the chapter. The ethnographic, participatory home based proposal seeks to work through the tensions within how specific practices in people's everyday lives produce different experiences and understanding exactly how these might work with clinical versions. The second proposal, the **Experience 4** based tool, accounts for the changing nature of MS and how it can impact on people's everyday lives from day to day. It is easy to understand how *Under and Over* could be the basis for a new form of **Experience 2** measurement, while nonetheless respecting **Experience 4**. How this artefact is capable of producing different experiences is conceptually and practically an interesting question for the future. Both proposals start to imagine how new technologies of experience could work amongst clinical tools, home environments and different MS ensembles. I am currently developing a research protocol to study *Under and Over* in people's homes which will follow on from the research of this thesis.

On a wider scale so to speak, this work sits within the changing context of MS research where clinical categories and understandings of the disease are being challenged. The practical work presented in this thesis and the table of experience proposes to contribute to this changing field through endorsing practice-based knowledge to contribute to some of the complex problems of the field. For example, in this changing treatment and research landscape of MS in the UK, the proposal suggests moving on from PROMs being static, population measures driven by economic pressures to open up the potential for them to be a tool to have real impact in people's daily lives. Ultimately, enabling a way for people to account for change in their condition. The proposals, as performative re-figuring's, suggest another way of thinking about patient measurement and engagement, arguing for and working with the expanded notions of experience I have identified. They do not transgress the present, nor confirm it, but add to it. The implications of this is that these different versions of experience, which are not intended by medicine and design practices thus become usable by other areas and other reasons which are more than functional, positivist

tools. They become ideas to re-imagine what patients, and their activities that generate experiences, could become.

Central to all of this future work is the continuation of my research position with the Barts MS research team at QMUL where I now occupy the role of a Lecturer. This will ensure that I can continue to build on our collaboration as a design researcher based within a clinical team and hope to build a hub for this kind of work in the future. This would involve the continuation of publications, presentations and teaching around the topic of study.

In conclusion, this thesis set out to answer the following research question: how can design-led research redo 'patient experience' for people with MS? I can now answer this question through the reflecting on the work of this thesis which has identified different versions of patient experience and understood how they are influenced by social science, healthcare practices and design. Through the practice-based work in the pilot studies and research study it has suggested ways in which design can contribute to the performativity of patient experience building on the key argument of this thesis that specific versions of patient experience are an upshot of the measurement and representational devices. Finally, by delivering a research study which explores how design-led research can uncover and explore the situated enactments of MS I concluded by creating two proposals which explore how changing material practice and representational devices enables alternative experiences to be produced. By outlining the different versions, or lenses with which to view experience practices, this thesis has pointed out how this can be potentially useful to clinicians and researchers. Equally this work acknowledges a broader range of patient experience which is potentially rewarding, and less alienating for patients, as they can recognize their experience in ways that they haven't been able to do before.

References

Akrich, M. (1992) The De-Scription of Technical Objects, In Bijker, W. E. and Law, J. (eds.), *Shaping technology/building society: studies in sociotechnical change, Inside technology*, Cambridge, Mass, MIT Press.

Anand, A. (2011) Professional Conferences, Unprofessional Conduct, *Medical Journal Armed Forces India*, 67(1), pp. 2–6.

Andersen, L. B., Danholt, P., Halskov, K., Hansen, N. B. and Lauritsen, P. (2015) Participation as a matter of concern in participatory design, *CoDesign*, 11(3–4), pp. 250–261.

Anon (2015) Digesting Science, *Digesting Science*, [online] Available at: http://digestingscience.co.uk/ (Accessed 14 June 2015).

Arnstein, S. R. (1969) A Ladder Of Citizen Participation, *Journal of the American Institute of Planners*, 35(4), pp. 216–224.

Austin, J. L. (1976) *How to do things with words: the William James lectures delivered at Harvard University in 1955*, London, Oxford Univ. Press.

Barad, K. (2003) Posthumanist performativity: Toward an understanding of how matter comes to matter, *Signs*, 28(3), pp. 801–831.

Barad, K. M. (2007) *Meeting the universe halfway: quantum physics and the entanglement of matter and meaning*, Durham, Duke University Press.

Barnes, B. (1983) *T.S. Kuhn and Social Science*, London, Macmillan.

Barnes, C., Oliver, M. and Barton, L. (eds.) (2002) Disability studies today, Cambridge, UK ; Malden, MA, Polity Press in association with Blackwell Publishers.

Barrett, L., Cano, S., Zajicek, J. and Hobart, J. (2013) Can the ABILHAND handle manual ability in MS?, *Multiple Sclerosis Journal*, 19(6), pp. 806–815.

Barts Health (2018) Patients' experience at Barts Health hospitals is improving, *Barts Health NHS Trust Blog*, [online] Available at: https://bartshealth.nhs.uk/news/patients-experience-at-barts-health-hospitals-is-improving-3604 (Accessed 20 September 2018).

Bate, P. and Robert, G. (2007) *Bringing user experience to healthcare improvement: the concepts, methods and practices of experience-based design*, Oxford; New York, Radcliffe Pub.

Bate, P. and Robert, G. (2006) Experience-based design: from redesigning the system around the patient to co-designing services with the patient, *Quality and Safety in Health Care*, 15(5), pp. 307–310.

Ben Hayoun, N. (2017) *Homo Faber and Animal Laborans met in Mission Control to Dream of Space: The Design of Experiences at NASA*. PhD Thesis. London, Royal Holloway, University of London.

Benjaminy, S., Schepmyer, A., Illes, J. and Traboulsee, A. (2018) Resilience, trust, and civic

engagement in the post-CCSVI era, *BMC Health Services Research*, 18(1).

Benz, P. (ed.) (2015) *Experience design: concepts and case studies*, London ; New York, Bloomsbury Academic.

Berg, M. (1996) Practices of reading and writing: the constitutive role of the patient record in medical work, *Sociology of Health & Illness*, 18(4), pp. 499–524.

Berg, M. (1997) Problems and promises of the protocol, *Social Science & Medicine*, 44(8), pp. 1081–1088.

Berg, M. (1998) The Politics of Technology: On Bringing Social Theory into Technological Design, *Science, Technology & Human Values*, 23(4), pp. 456–490.

Berg, M. and Bowker, G. (1997) The Multiple Bodies of the Medical Record: Toward a Sociology of an Artifact, *The Sociological Quarterly*, 38(3), pp. 513–537.

Berg, M. and Mol, A. (1998) *Differences in medicine: unraveling practices, techniques, and bodies*, Durham, N.C., Duke University Press.

Bethoux, F. and Bennett, S. (2011) Evaluating Walking in Patients with Multiple Sclerosis: Which Assessment Tools Are Useful in Clinical Practice?, *International Journal of MS Care*, 13(1), pp. 4–14.

Bingham, N. (2008) Slowing things down: Lessons from the GM controversy, *Geoforum*, 39(1), pp. 111–122.

Bjerknes, G., Ehn, P., Kyng, M. and Nygaard, K. (eds.) (1987) *Computers and democracy: a Scandinavian challenge*, Aldershot [Hants, England] ; Brookfield [Vt.], USA, Avebury.

Black, N. and Jenkinson, C. (2009) Measuring patients' experiences and outcomes, *BMJ*, 339(July 02 1), pp. 2495–2495.

Blomberg, J., Burrell, M. and Guest, G. (2003) An Ethnographic Approach to Design, In Sears, A. (ed.), *The Human-Computer Interaction Handbook*, London, Lawrence Erlbaum Associates, pp. 964–986, [online] Available at: http://www.crcnetbase.com/doi/abs/10.1201/b11963-52 (Accessed 2 November 2016).

Bloor, D. (1999) Anti-Latour, *Studies in History and Philosophy of Science Part A*, 30(1), pp. 81–112.

Bloor, D. (1976) *Knowledge and social imagery*, Chicago, University of Chicago Press.

Boaz, A., Biri, D. and McKevitt, C. (2016) Rethinking the relationship between science and society: Has there been a shift in attitudes to Patient and Public Involvement and Public Engagement in Science in the United Kingdom?, *Health Expectations*, 19(3), pp. 592–601.

Boehner, K., Gaver, W. and Boucher, A. (2012) Probes, In Lury, C. and Wakeford, N. (eds.), *Inventive Methods: The Happening of the Social*, Routledge, pp. 185–201.

Bossavit, B. and Parsons, S. (2018) Outcomes for design and learning when teenagers with autism codesign a serious game: A pilot study, *Journal of Computer Assisted Learning*, 34(3), pp. 293–305.

Boswijk, A., Thijssen, T. and Peelen, E. (2007) *The Experience Economy a new perspective*, AmsterdambPearson Education.

Bowen, S., Dearden, A., Wright, P., Wolstenholme, D. and Cobb, M. (2010) Participatory healthcare service design and innovation, In *ACM Press*, p. 155, [online] Available at: http://portal.acm.org/citation.cfm?doid=1900441.1900464 (Accessed 29 November 2014).

Bowen, S., McSeveny, K., Lockley, E., Wolstenholme, D., Cobb, M. and Dearden, A. (2013) How was it for you? Experiences of participatory design in the UK health service, *CoDesign*, 9(4), pp. 230–246.

Bowker, G. C. and Star, S. L. (2000) *Sorting things out: classification and its consequences, Inside technology*, First paperback edition, Cambridge, Massachusetts London, England, The MIT Press.

Boyle, D. and Harris, M. (2009) *The challenge of co-production: how equal partnerships between professionals and the public are crucial to improving public services,* Discussion paper, London, New Economics Foundation.

Brandt, E. (2006) Designing Exploratory design Games a framework for particiaption in participatory design?, In *Proceedings of the ninth conference on Participatory design Expanding boundaries in design* - Volume 1, ACM Digital Library, [online] Available at: http://dl.acm.org/citation.cfm?id=1147261 (Accessed 11 February 2016).

Brotchie, A. and Gooding, M. (eds.) (1995) *A book of surrealist games: including the little surrealist dictionary*, Boston, Shambhala Redstone Editions : Distributed in the United States by Random House.

Buchenau, M. and Suri, J. F. (2000) Experience prototyping, In *ACM Press*, pp. 424–433, [online] Available at: http://portal.acm.org/citation.cfm?doid=347642.347802 (Accessed 16 April 2015).

Buck, D., Gamble, C., Dudley, L., Preston, J., Hanley, B., Williamson, P. R., Young, B. and The EPIC Patient Advisory Group (2014) From plans to actions in patient and public involvement: qualitative study of documented plans and the accounts of researchers and patients sampled from a cohort of clinical trials, *BMJ Open*, 4(12), p. 6400.

Bury, M. (1991) The sociology of chronic illness: a review of research and prospects, Sociology of Health and Illness, 13(4), pp. 451–468.

Butler, J. (1993) *Bodies that matter: on the discursive limits of 'sex',* Routledge classics, Abingdon, Oxon ; New York, NY, Routledge.

Butler, J. (1990) *Gender trouble: feminism and the subversion of identity*, Routledge classics,

New York, Routledge.

Butler, J. (1988) Performative Acts and Gender Constitution: An Essay in Phenomenology and Feminist Theory, *Theatre Journal*, 40(4), p. 519.

Cain, J. (2010) Experience-Based Design: Toward a Science of Artful Business Innovation, *Design Management Journal* (Former Series), 9(4), pp. 10–16.

Callon, M. (1986) *Some elements of a sociology of translation*, Cambridge, MA: The MIT Press.

Callon, M. (1991) Techno-economic network and irreversibility, In Law, J. (ed.), *A sociology of monsters: essays on power, technology, and domination*, Sociological review monograph, London New York, Routledge, pp. 132–164.

Callon, M. (2015) The role of hybrid communities and socio-technical arrangements in the participatory design, *Journal of the Center for Information Studies*, (5), pp. 3–10.

Callon, M. (2004) The role of hybrid communities and socio-technical arrangements in the participatory design, *ResearchGate*, 5(3), [online] Available at: https://www.researchgate.net/publication/255620728_The_role_of_hybrid_communities_and_socio-technical_arrangements_in_the_participatory_design (Accessed 15 April 2016).

Callon, M. (2006) *What does it mean to say that economics is performative?*, CSI Working Papers Series, Centre de Sociologie de l'Innovation (CSI), Mines ParisTech, [online] Available at: http://econpapers.repec.org/paper/emnwpaper/005.htm (Accessed 15 April 2016).

Callon, M. and Law, J. (1997) Agency and the Hybrid Collectif, In Smith, B. H. and Plotnitsky, A. (eds.), *Mathematics, Science, and Postclassical Theory*, Duke University Press, pp. 95–117, [online] Available at: https://read.dukeupress.edu/books/book/656/chapter/130944/ (Accessed 13 November 2018).

Callon, M. and Rabeharisoa, V. (2004) Articulating bodies: the case of muscular dystrophies, *Body and Society*, 22(10), pp. 183–203.

Cano, S. and Hobart (2011) The problem with health measurement, *Patient Preference and Adherence*, p. 279.

Carel, H. (2012) Phenomenology as a Resource for Patients, *Journal of Medicine and Philosophy*, 37(2), pp. 96–113.

Casper, M. J. and Berg, M. (1995) Constructivist Perspectives on Medical Work: Medical Practices and Science and Technology Studies: Introduction, *Science, Technology, & Human Values*, 20(4), pp. 395–407.

Cella, D. F., Dineen, K., Arnason, B., Reder, A., Webster, K. A., karabatsos, G., Chang, C., Lloyd, S., Steward, J. and Stefoski, D. (1996) Validation of the functional assessment of multiple sclerosis quality of life instrument, *Neurology*, 47(1), pp. 129–139.

Cerqueira, J. J., Compston, D. A. S., Geraldes, R., Rosa, M. M., Schmierer, K., Thompson,

A., Tinelli, M. and Palace, J. (2018) Time matters in multiple sclerosis: can early treatment and long-term follow-up ensure everyone benefits from the latest advances in multiple sclerosis?, Journal of Neurology, *Neurosurgery & Psychiatry*, 89(8), pp. 844–850.

Chalmers, D. J. (1995) Facing up to the problem of consciousness, *Journal of Consciousness Studies*, 2(3), pp. 200–219.

Ciotti, J. R. and Cross, A. H. (2018) Disease-Modifying Treatment in Progressive Multiple Sclerosis, *Current Treatment Options in Neurology*, 20(5), [online] Available at: http://link.springer.com/10.1007/s11940-018-0496-3 (Accessed 2 January 2019).

Clatworthy, S. (2011) Service Innovation Through Touch-points: Development of an Innovation Toolkit for the First Stages of New Service Development, *International Journal of Design*, 5(2), pp. 15–28.

Collins, H. M. (1983) An Empirical Relativist Programme in the Sociology of Scientific Knowledge, In Knorr-Cetina, K. and Mulkay, M. J. (eds.), *Science Observed: Perspectives on the Social Study of Science*, London, Sage, pp. 85–113.

Collins, H. M. and Evans, R. (2002) The Third Wave of Science Studies: Studies of Expertise and Experience, *Social Studies of Science*, 32(2), pp. 235–296.

Collins, H. M. and Yearley, S. (1992) Epistemological chicken, In *Science as Practice and Culture*, Chicago, The University of Chicago Press, pp. 301–326.

Commins, S., McCormack, K., Callinan, E., Fitzgerald, H., Molloy, E. and Young, K. (2013) Manipulation of visual information does not change the accuracy of distance estimation during a blindfolded walking task, *Human Movement Science*, 32(4), pp. 794–807.

Cottam, H. and Leadbeater, C. (2004) *Red Paper 01 Health: Co-creating Services*, Design Council.

Cross, N. (1982) Designerly Ways of Knowing, *Design Issues*, 3(4), pp. 221–227.

Crotty, M. (1996) *Phenomenology and nursing research*, South Melbourne, Victoria, Churchill Livingstone.

Dagognet, F. (1969) *Tableaux et Langages de la Chimie*, Paris, Le Seuil.

Danholt, P. (2005a) How Is User-Centered Design Interested in Users? A Posthumanist Approach, In *Proceedings of the 28th Information Systems Research Seminar in Scandinavia (IRIS)*, Kristiansand, Norway, IRIS Association.

Danholt, P. (2008) Interacting Bodies: Posthuman Enactments of the Problem of Diabetes: Relating Science, Technology and Society-studies, *User-Centered Design and Diabetes Practices*, Roskilde Universitet.

Danholt, P. (2005b) Prototypes as performative, In *ACM Press*, p. 1, [online] Available at: http://portal.acm.org/citation.cfm?doid=1094562.1094564 (Accessed 26 January 2015).

Dennett, D. C. (1991) *Consciousness explained*, 1st ed, Boston, Little, Brown and Co.

Department of Health (2008) *High Quality Care For All: NHS Next Stage Review final report*, London, The Stationery Office.

Department of Health (2018) *NHS Outcomes Framework Indicators - November 2018 Release*, England, Department of Health, [online] Available at: https://digital.nhs.uk/data-and-information/publications/clinical-indicators/nhs-outcomes-framework/current (Accessed 14 December 2018).

Derrida, J. (1988) *Limited Inc*, Evanston, IL, Northwestern University Press.

Dewey, J. (1934) *Art as experience*, New York, Berkley Pub. Group.

Diedrich, L. (2005) Introduction: Genealogies of Disability: Historical emergences and everyday enactments, *Cultural Studies*, 19(6), pp. 649–666.

Dobson, R. and Giovannoni, G. (2012) *Multiple Sclerosis: Visual Guide for Clinicians*, Oxford, Clinical Publishing.

Donetto, S., Pierri, P., Tsianakas, V. and Robert, G. (2015) Experience-based Co-design and Healthcare Improvement: Realizing Participatory Design in the Public Sector, *The Design Journal*, 18(2), pp. 227–248.

Donetto, S., Tsianakas, V. and Robert, G. (2014) *Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions*, London, King's College London.

Dong, H. and Vivat, B. (2008) Co-Design Involving people with disabilities, In *Proceedings of the International Conference on Engineering and Product Design Education*, 4 & 5 September 2008, Universitat Politecnica De Catalunya, Barcelona, Spain.

Dowrick, A. S., Wootten, A. C., Murphy, D. G. and Costello, A. J. (2015) 'We Used a Validated Questionnaire': What Does This Mean and Is It an Accurate Statement in Urologic Research?, *Urology*, 85(6), pp. 1304–1311.

Dudhwala, F., Boylan, A.-M., Williams, V. and Powell, J. (2017) Viewpoint: What counts as online patient feedback, and for whom?, *Digital Health*, 3, p. 205.

Dunne, A. and Raby, F. (2001) *Design noir: the secret life of electronic objects*, Basel, Birkhäuser.

Ehn, P. (2008) Participation in design things, In *Proceedings of the Tenth Anniversary Conference on Participatory Design 2008*, PDC '08, Indianapolis, IN, USA, Indiana University, pp. 92–101, [online] Available at: http://dl.acm.org/citation.cfm?id=1795234.1795248.

Ehn, P. (1989) *Work-oriented design of computer artifacts*, 2. ed, Stockholm, Arbetslivcentrum.

Ehn, P. and Kyng, M. (1991) Cardboard Computers: Mocking-it-up or Hands-on the Future,

In Greenbaum, J. M. and Kyng, M. (eds.), *Design at work: cooperative design of computer systems*, Hillsdale, N.J, L. Erlbaum Associates.

Ellwood, P. M. (1988) A Technology of Patient Experience, *The New England Journal of Medicine*, 318(23), pp. 1549–1556.

Eriksen, M. A. (2012) *Material matters in co-designing formatting & staging with participating materials in co-design projects, events & situations*, Malmö, Faculty of Culture and Society, Malmö University, [online] Available at: http://dspace.mah.se/handle/2043/13674 (Accessed 11 November 2018).

Evenson, S. and Dubberly, H. (2009) Designing for Service: Creating an Experience Advantage, In Salvendy, G. and Karwowski, W. (eds.), *Introduction to Service Engineering*, Hoboken, NJ, USA, John Wiley & Sons, Inc., pp. 403–413, [online] Available at: http://doi.wiley.com/10.1002/9780470569627.ch19 (Accessed 9 December 2018).

Feys, P., Lamers, I., Francis, G., Benedict, R., Phillips, G., LaRocca, N., Hudson, L. D., Rudick, R. and Multiple Sclerosis Outcome Assessments Consortium (2017) The Nine-Hole Peg Test as a manual dexterity performance measure for multiple sclerosis, *Multiple Sclerosis Journal*, 23(5), pp. 711–720.

Fischer, J. S., Rudick, R. A., Cutter, G. R., Reingold, S. C. and National MS Society Clinical Outcomes Assessment Task Force (1999) The Multiple Sclerosis Functional Composite measure (MSFC): an integrated approach to MS clinical outcome assessment, *Multiple Sclerosis*, 5(4), pp. 244–250.

Ford, H. L., Gerry, E., Tennant, A., Whalley, D., Haigh, R. and Johnson, M. H. (2001) Developing a disease-specific quality of life measure for people with multiple sclerosis, *Clinical Rehabilitation*, 15(3), pp. 247–258.

Foucault, M., Martin, L. H., Gutman, H. and Hutton, P. H. (eds.) (1988) *Technologies of the self: a seminar with Michel Foucault*, Amherst, University of Massachusetts Press.

Fraser, M. (2009) Facts, Ethics and Event, In Jensen, C. B. and Rødje, K. (eds.), *Deleuzian Intersections Science, Technology and Anthropology*, New York, Berghahn Books, Inc., [online] Available at: http://public.eblib.com/choice/publicfullrecord.aspx?p=544318 (Accessed 16 April 2015).

Frayling, C. (1993) *Reseach in art and design*, London, Royal College of Art.

Freeman, J. A., Hobart, J., Langdon, D. and Thompson, A. (2000) Clinical appropriateness: a key factor in outcome measure selection: the 36 item short form health survey in multiple sclerosis, *Journal of Neurology, Neurosurgery & Psychiatry*, 68(2), pp. 150–156.

Freire, K. and Sangiorgi, D. (2010) Service design and healthcare innovation : from consumption, to co-production to co-creation, In *Proceedings of the Nordic Service Design Conference*, 1-3 December 2010, Linkoping, Sweden.

Fujimura, J. H. (1987) Constructing `Do-able' Problems in Cancer Research: Articulating

Alignment, *Social Studies of Science*, 17(2), pp. 257–293.

Fujimura, J. H. (1992) Crafting Science: Standardized Packages, Boundary Objects, and 'Translation.', In Pickering, A. (ed.), *Science as Practice and Culture*, University of Chicago Press, pp. 168–211.

Gafson, A. R. and Giovannoni, G. (2014) CCSVI-A. A call to clinicans and scientists to vocalise in an Internet age, *Multiple Sclerosis and Related Disorders*, 3(2), pp. 143–146.

Galis, V. (2011) Enacting disability: how can science and technology studies inform disability studies?, *Disability & Society*, 26(7), pp. 825–838.

Garfinkel, H. (1967) *Studies in Ethonomethodology*, 1st ed, Englewood cloffs, New Jersey, Prentice-Hall, Inc.

Gaver, B., Dunne, T. and Pacenti, E. (1999) Design: Cultural probes, *Interactions*, 6(1), pp. 21–29.

Gaver, W., Michael, M., Kerridge, T., Wilkie, A., Boucher, A., Ovalle, L. and Plummer-Fernandez, M. (2015) Energy Babble: Mixing Environmentally-Oriented Internet Content to Engage Community Groups, In *ACM Press*, pp. 1115–1124.

Gaver, W. W., Boucher, A., Pennington, S. and Walker, B. (2004) Cultural probes and the value of uncertainty, *Interactions*, 11(5), p. 53.

Giantomaso, T., Makowsky, L., Ashworth, N. L. and Sankaran, R. (2003) The validity of patient and physician estimates of walking distance, *Clinical Rehabilitation*, 17(4), pp. 394–401.

Gillard, S., Simons, L., Turner, K., Lucock, M. and Edwards, C. (2012) Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study, *Qualitative Health Research*, 22(8), pp. 1126–1137.

Giovannoni, G. (2014) ASCEND Trial: why I think the natalizumab in SPMS trial will be negative, *Barts MS Research Blog*, [online] Available at: http://multiple-sclerosis-research.blogspot.com/2014/11/ascend-trial-why-i-think-natalizumab-in.html (Accessed 11 February 2016).

Giovannoni, G. (2017) Clinic Speak: An informed resource for people with MS, *Clinic Speak*, [online] Available at: http://www.clinicspeak.com (Accessed 1 July 2017).

Giovannoni, G. (2015) NewsSpeak: the aftermath of the negative ASCEND trial, *Barts MS Research Blog*, [online] Available at: http://multiple-sclerosis-research.blogspot.com/2015/10/newsspeak-aftermath-of-negative-ascend.html (Accessed 22 October 2015).

Giovannoni, G. (2016a) ThinkHand: what iconic image captures hand function best?, *Barts MS Research Blog*, [online] Available at: http://multiple-sclerosis-research.blogspot.com/2016/07/thinkhand-what-iconic-image-captures.html (Accessed 11 February 2016).

Giovannoni, G. (2016b) Understanding your risk of PML with Tysabri, *Clinic Speak*, [online] Available at: http://www.clinicspeak.com/understanding-pml-risk-on-tysabri/ (Accessed 15 June 2016).

Giovannoni, G., Cutter, G., Sormani, M. P., Belachew, S., Hyde, R., Koendgen, H., Knappertz, V., Tomic, D., Leppert, D., Herndon, R., Wheeler-Kingshott, C. A. M., Ciccarelli, O., Selwood, D., di Cantogno, E. V., Ben-Amor, A.-F., Matthews, P., Carassiti, D., Baker, D. and Schmierer, K. (2017) Is multiple sclerosis a length-dependent central axonopathy? The case for therapeutic lag and the asynchronous progressive MS hypotheses, *Multiple Sclerosis and Related Disorders*, 12, pp. 70–78.

Goffman, E. (1990) *The presentation of self in everyday life*, London, Penguin.

Gomart, E. and Hennion, A. (1999) A sociology of attachment: music amateurs, drug users, *The Sociological Review*, 47(S1), pp. 220–247.

Goodrich, J. and Cornwell, J. (2008) *Seeing the person in the patient: the Point of Care review paper*, London, King's Fund.

Great Britain and Department of Health (2010) *Equity and excellence: Liberating the NHS*, Norwich, The Stationary Office.

Greco, M. (2012) The classification and nomenclature of 'medically unexplained symptoms': Conflict, performativity and critique, *Social Science & Medicine*, 75(12), pp. 2362–2369.

Greenbaum, J. M. and Kyng, M. (eds.) (1991) *Design at work: cooperative design of computer systems*, Hillsdale, N.J, L. Erlbaum Associates.

Greenhalgh, T. and Hurwitz, B. (eds.) (1998) *Narrative based medicine: dialogue and discourse in clinical practice*, Medical research, London, BMJ Books.

Gurkan, M., Ozakbas, S., Piri Cinar, B., Bircan Kursun, B., Oz, D. and Ozturk, O. (2013) Paced auditory serial addition test: normative data in a Turkish population, In *Proceedings for ECTRIMS 2013. October 2-5, 2013*, Copenhagen, Denmark.

Guyatt, G., Cairns, J., Churchill, D., Cook, D., Haynes, B., Hirsh, J., Irvine, J., Levine, M., Levine, M., Nishikawa, J., Sackett, D., Brill-Edwards, P., Gerstein, H., Gibson, J., Jaeschke, R., Kerigan, A., Neville, A., Panju, A., Detsky, A., Enkin, M., Frid, P., Gerrity, M., Laupacis, A., Lawrence, V., Menard, J., Moyer, V., Mulrow, C., Links, P., Oxman, A., Sinclair, J. and Tugwell, P. (1992) Evidence-based medicine: A new approach to teaching the practice of medicine, *JAMA*, 268(17), pp. 2420–2425.

Halpern, J. (2003) What is clinical empathy?, *Journal of General Internal Medicine*, 18(8), pp. 670–674.

Haraway, D. (1994) A Game of Cat's Cradle: Science Studies, Feminist Theory, Cultural Studies, *Configurations*, 2(1), pp. 59–71.

Haraway, D. (1988) Situated Knowledges: The Science Question in Feminism and the

Privilege of Partial Perspective, *Feminist Studies*, 14(3), pp. 575–599.

Haraway, D. J. (1991) *Simians, cyborgs, and women: the reinvention of nature.*, New York, Routledge.

Haraway, D. J. (2008) *When species meet, Posthumanities*, Minneapolis, University of Minnesota Press.

Health and Social Care Act (2001) *Health and Social Care Act*, [online] Available at: http://www.legislation.gov.uk/ukpga/2001/15/pdfs/ukpga_20010015_en.pdf (Accessed 11 February 2016).

Heidegger, M. (1927) *Being and time*, 35th ed, Malden, Blackwell.

Henriques, J., Holloway, W., Urwin, C., Venn, C. and Walkerdine, V. (eds.) (1998) *Changing the subject: psychology, social regulation, and subjectivity*, London ; New York, Routledge.

Hielscher, S., Fisher, T. and Cooper, T. (2007) How often do you wash your hair? design as disordering: everyday routines, human object theories, probes and sustainablity., In *7th European Academy of Design Conference (EAD07): Dancing with disorder: design, discourse and disorder*, Izmir, Turkey, 11-13 April 2007 [online] Available at: http://fadf.ieu.edu.tr/ead07/# (Accessed 19 February 2017).

Hobart, J. (2001) The Multiple Sclerosis Impact Scale (MSIS-29): A new patient-based outcome measure, *Brain*, 124(5), pp. 962–973.

Hobart, J. C., Riazi, A., Lamping, D. L., Fitzpatrick, R. and Thompson, A. J. (2005) How responsive is the Multiple Sclerosis Impact Scale (MSIS-29)? A comparison with some other self report scales, *Journal of Neurology, Neurosurgery, and Psychiatry*, 76(11), pp. 1539–1543.

Hobart, J. and Cano, S. (2009) Improving the evaluation of therapeutic interventions in multiple sclerosis: the role of new psychometric methods, *Health Technology Assessment*, 13(12), [online] Available at: http://www.journalslibrary.nihr.ac.uk/hta/volume-13/issue-12 (Accessed 4 August 2016).

Hollway, W. and Jefferson, T. (2000) *Doing qualitative research differently: free association, narrative and the interview method*, London ; Thousand Oaks, Calif, SAGE.

Hughes, J., King, V., Rodden, T. and Andersen, H. (1995) The role of ethnography in interactive systems design, *Interactions*, 2(2), pp. 56–65.

Hulley, S. B., Cummings, S. R., Browner, W. S., Grady, D. G. and Newman, T. B. (2007) *Designing clinical research*, 3rd ed, Philadelphia, PA, Lippincott Williams & Wilkins.

Husserl, E. (1931) *Ideas: General Introduction to Pure Phenomenology*, Routledge classics, London ; New York, Routledge.

International Women in MS (2018) Gender Inequities in the Multiple Sclerosis Community: A Call for Action, *Annals of Neurology*, 84(6), pp. 958–959.

Irwin, A. (2006) The Politics of Talk: Coming to Terms with the 'New' Scientific Governance, *Social Studies of Science*, 36(2), pp. 299–320.

Irwin, A. and Michael, M. (2003) *Science, social theory and public knowledge*, Maidenhead ; Philadelphia, Open University Press.

Ives, J., Damery, S. and Redwod, S. (2013) PPI, paradoxes and Plato: who's sailing the ship?, *Journal of Medical Ethics*, 39(3), pp. 181–185.

Jefferson, G. (1979) A technique for inviting laughter and its subsequent acceptance/ declination, In Psathas, G. (ed.), *Everyday language: Studies in ethnomethodology*, New York, NY, Irvington Publishers, pp. 79–96.

Jeffrey, D. (2016) Empathy, sympathy and compassion in healthcare: Is there a problem? Is there a difference? Does it matter?, *Journal of the Royal Society of Medicine*, 109(12), pp. 446–452.

Jenkinson, C. and Fitzpatrick, R. (2013) Patient Reported Outcomes, In Ziebland, S., Coulter, A., Calabrese, J. D., and Locock, L. (eds.), *Understanding and using health experiences: improving patient care*, Oxford, Oxford University Press, pp. 72–80.

Jerak-Zuiderent, S. (2015) Keeping Open by Re-Imagining Laughter and Fear, *The Sociological Review*, 63(4), pp. 897–921.

Jonas, W. (2007) Design Research and its Meaning to the Methodological Development of the Discipline, In Michel, R. (ed.), *Design Research Now: Essays and Selected Projects*, Basel, Birkhäuser Basel, pp. 187–206, [online] Available at: http://dx.doi.org/10.1007/978-3-7643-8472-2_11.

Jönsson, L. (2014) *Design Events: On explorations of a non-anthropocentric framework in design*. Phd Thesis, Copenhagen, Denmark, Royal Danish Academy of Fine Arts School of Design.

Kapoor, R., Ho, P.-R., Campbell, N., Chang, I., Deykin, A., Forrestal, F., Lucas, N., Yu, B., Arnold, D. L., Freedman, M. S., Goldman, M. D., Hartung, H.-P., Havrdová, E. K., Jeffery, D., Miller, A., Sellebjerg, F., Cadavid, D., Mikol, D., Steiner, D., Bartholomé, E., D'Hooghe, M., Pandolfo, M., Van Wijmeersch, B., Bhan, V., Blevins, G., Brunet, D., Devonshire, V., Duquette, P., Freedman, M., Grand'Maison, F., Jacques, F., Lapierre, Y., Lee, L., Morrow, S., Yeung, M., Dufek, M., Havrdová, E. K., Kanovsky, P., Stetkarova, I., Talabova, M., Frederiksen, J., Kant, M., Petersen, T., Ravnborg, M., Sellebjerg, F., Airas, L., Elovaara, I., Eralinna, J.-P., Sarasoja, T., Al Khedr, A., Brassat, D., Brochet, B., Camu, W., Debouverie, M., Laplaud, D., Lebrun Frenay, C., Pelletier, J., Vermersch, P., Vukusi, S., Baum, K., Berthele, A., Faiss, J., Flachenecker, P., Hohlfeld, R., Krumbholz, M., Lassek, C., Maeurer, M., Meuth, S., Ziemssen, T., Hardiman, O., McGuigan, C., Achiron, A., Karussis, D., Bergamaschi, R., Morra, V. B., Comi, G., Cottone, S., Grimaldi, L., Mancardi, G. L., Massacesi, L., Nocentini, U., Salvetti, M., Scarpini, E., Sola, P., Tedeschi, G., Trojano, M., Zaffaroni, M., Frequin, S., Hupperts, R., Killestein, J., Schrijver, H., Van Dijl, R., van Munster, E., Czarnecki, M., Drozdowski, W., Fryze, W., Hertmanowska, H., Ilkowski, J., Kaminska, A., Klodowska-Duda, G., Maciejowski, M., Motta, E., Podemski,

R., Potemkowski, A., Rog, T., Selmaj, K., Stelmasiak, Z., Stepien, A., Tutaj, A., Zaborski, J., Boyko, A., Chefranova, Z., Evdoshenko, E., Khabirov, F., Sivertseva, S., Yakupov, E., Alvarez Cermeño, J. C., Escartin, A., Fernandez, O. F., Garcia-Merino, A., Hernandez Perez, M. A., Ayuso, G. I., Lallana, J. M., Gairin, X. M., Oreja-Guevara, C., Saiz Hinarejos, A., Gunnarsson, M., Lycke, J., Martin, C., Piehl, F., Roshanisefat, H., Sundstrom, P., Duddy, M., Gran, B., Harrower, T., Hobart, J., Kapoor, R., Lee, M., Mattison, P., Nicholas, R., Pearson, O., Rashid, W., Rog, D., Sharrack, B., Silber, E., Turner, B., Williams, A., Woolmore, J., Young, C., Bandari, D., Berger, J., Camac, A., Cohan, S., Conway, J., Edwards, K., Fabian, M., Florin, J., Freedman, S., Garwacki, D., Goldman, M., Harrison, D., Herrman, C., Huang, D., Javed, A., Jeffery, D., Kamin, S., Katsamakis, G., Khatri, B., Langer-Gould, A., Lynch, S., Mattson, D., Miller, T., Miravalle, A., Moses, H., Muley, S., Napier, J., Nielsen, A., Pachner, A., Pardo, G., Picone, M., Robertson, D., Royal, W., Sheppard, C., Thrower, B., Twyman, C., Waubant, E., Wendt, J., Yadav, V., Zabad, R. and Zarelli, G. (2018) Effect of natalizumab on disease progression in secondary progressive multiple sclerosis (ASCEND): a phase 3, randomised, double-blind, placebo-controlled trial with an open-label extension, *The Lancet Neurology*, 17(5), pp. 405–415.

Kearney, H., Grussu, F., Schneider, T., Zhang, H., Alexander, D. and Ciccarelli, O. (2013) Neurite orientation dispersion and density imaging in the multiple sclerosis spinal cord, In *Proceedings for ECTRIMS 2013. October 2-5, 2013*, Copenhagen, Denmark.

Kensing, F., Simonsen, J. and Bødker, K. (1998) MUST - A Method for Participatory Design, *Human-Computer Interaction*, 13(2).

Kerridge, T. (2015) *Designing Debate: The Entanglement of Speculative Design and Upstream Engagement*. PhD Thesis, London, Goldsmiths, University of London.

Knorr-Cetina, K. (1981) *The manufacture of knowledge: an essay on the constructivist and contextual nature of science, Pergamon international library of science, technology, engineering, and social studies*, Oxford ; New York, Pergamon Press.

Knutz, E., Markussen, T. and Thomsen, S. M. (2018) Materiality in probes: three perspectives for co-exploring patient democracy, *CoDesign*, pp. 1–21.

Krueger, R. A. and Casey, M. A. (2009) *Focus groups: a practical guide for applied research*, 4th ed, Los Angeles, SAGE.

Kuhn, T. S. (1969) *The Structure of scientific revolutions, International encyclopedia of unified science Foundations of the unity of science*, Chicago, Ill, Chicago Univ. Press.

Kurtzke, J. F. (1983) Rating neurologic impairment in multiple sclerosis: an expanded disability status scale (EDSS), *Neurology*, 33(11), pp. 1444–1452.

Lamers, I. and Feys, P. (2014) Assessing upper limb function in multiple sclerosis, *Multiple Sclerosis Journal*, 20(7), pp. 775–784.

LaRocca, N. G., Ritvo, P. G., Miller, D. M., Fischer, J. S., Andrews, H. and Paty, D. W. (1996) 'Quality of Life' Assessment in Multiple Sclerosis Clinical Trials: Current Status and Strategies for Improving Multiple Sclerosis Clinical Trial Design, In Goodkin, D. E.

and Rudick, R. A. (eds.), *Multiple Sclerosis: Advances in Clinical Trial Design, Treatment and Future Perspectives*, London, Springer London, pp. 145–160, [online] Available at: https://doi.org/10.1007/978-1-4471-1271-6_7.

Latimer, J. (2018) Afterword: materialities, care, 'ordinary affects', power and politics, *Sociology of Health & Illness*, 40(2), pp. 379–391.

Latimer, J. (1998) Organizing context: nurses' assessments of older people in an acute medical unit, *Nursing Inquiry*, 5(1), pp. 43–57.

Latour, B. (1990) Drawing things together, In Lynch, M. and Woolgar, S. (eds.), *Representation in scientific practice*, Cambridge, Mass., MIT Press.

Latour, B. (1999) On recalling ANT, *The Sociological Review*, 47(S1), pp. 15–25.

Latour, B. (2005a) *Reassembling the social: an introduction to actor-network-theory*, Clarendon lectures in management studies, Oxford ; New York, Oxford University Press.

Latour, B. (1987) *Science in action: how to follow scientists and engineers through society*, Cambridge, Mass., Harvard University Press.

Latour, B. (1988) *The pasteurization of France*, First Harvard University Press paperback ed, Cambridge, Mass., Harvard Univ. Press.

Latour, B. (2005b) *What is Given in Experience ? A Review of Isabelle Stengers 'Penser avec Whitehead'* | bruno-latour.fr, Boundary 2, 32(1), pp. 222–237.

Latour, B. (1992) Where are the missing masses? The sociology of a few mundane artifacts, In Bijker, W. and Law, J. (eds.), *Shaping Technology/Building Society: Studies in Sociotechnical Change*, Cambridge, Mass., MIT Press, pp. 225–258, [online] Available at: http://www.bruno-latour.fr/sites/default/files/50-MISSING-MASSES-GB.pdf (Accessed 15 April 2016).

Latour, B. (2004) Why Has Critique Run out of Steam? From Matters of Fact to Matters of Concern, *Critical Inquiry*, 30(2), pp. 225–248.

Latour, B. and Woolgar, S. (1986) *Laboratory life: the construction of scientific facts*, Princeton, N.J, Princeton University Press.

Law, J. (2004) *After methodology*, London, Routledge.

Law, J. and Hassard, J. (1999) Actor network theory and after, *The Sociological review monographs*, Oxford [England] ; Malden, MA, Blackwell/Sociological Review.

Law, J. and Singleton, V. (2003) Allegory and its others, In Nicolini, D., Gherardi, S., and Yanow, D. (eds.), *Knowing in Organizations: A Practice Based Approach*, New York, M. E. Sharp, pp. 225–254, [online] Available at: http://oro.open.ac.uk/22041/ (Accessed 19 April 2016).

Law, J. and Urry, J. (2004) Enacting the social, *Economy and Society*, 33(3), pp. 390–410.

Lawton, J. (2003) Lay experiences of health and illness: past research and future agendas: Lay experiences of health and illness, Sociology of Health & Illness, 25(3), pp. 23–40.

Learmonth, M. (2005) Doing Things with Words: The Case of 'Management' and 'Administration', *Public Administration*, 83(3), pp. 617–637.

Lezaun, J. (2007) A market of opinions: the political epistemology of focus groups, *The Sociological Review*, 55, pp. 130–151.

Lezaun, J. and Soneryd, L. (2007) Consulting citizens: technologies of elicitation and the mobility of publics, *Public Understanding of Science*, 16(3), pp. 279–297.

Licoppe, C. (2010) The 'Performative Turn' in Science and Technology Studies: Towards a linguistic anthropology of 'technology in action', *Journal of Cultural Economy*, 3(2), pp. 181–188.

Lin, W. -y. (2013) Displacement of Agency: The Enactment of Patients' Agency in and beyond Haemodialysis Practices, *Science, Technology & Human Values*, 38(3), pp. 421–443.

Löwgren, J. and Reimer, B. (2013) *Collaborative media: production, consumption, and design interventions*, Cambridge, Mass., MIT Press.

Lury, C. (2009) Brand As Assamblage: Assembling culture, *Journal of Cultural Economy*, 2(1–2), pp. 67–82.

Lury, C. (2018) *Routledge handbook of interdisciplinary research methods*, London, Routledge.

Lury, C. and Wakeford, N. (eds.) (2012) *Inventive methods: the happening of the social*, London ; New York, Routledge.

Lynch, M. (1985) Discipline and the Material Form of Images: An Analysis of Scientific Visibility, *Social Studies of Science*, 15(1), pp. 37–66.

Lynch, M. (2001) Ethnomethodology and the logic of practice, In Schatzki, T. R., Knorr-Cetina, K., and von Savigny, E. (eds.), *The Practice Turn in Contemporary Theory*, Routledge, pp. 131-148.

Macdonald, A. S. (2013) The Inner Resource: Enabling the Designer within Us All – A Case Study, *The Design Journal*, 16(2), pp. 175–196.

Mackenzie, D. (2006) Is Economics Performative? Option Theory and the Construction of Derivatives Markets, *Journal of the History of Economic Thought*, 28(01), p. 29.

MacKenzie, D. (2004) The big, bad wolf and the rational market: portfolio insurance, the 1987 crash and the performativity of economics, *Economy and Society*, 33(3), pp. 303–334.

MacKenzie, D. A. (ed.) (2008) *Do economists make markets? on the performativity of economics*. Princeton, NJ, Princeton Univ. Press.

MacKenzie, D. and Millo, Y. (2003) Constructing a Market, Performing Theory: The Historical Sociology of a Financial Derivatives Exchange, *American Journal of Sociology*, 109(1), pp. 107–145.

MacLurg, K., Reilly, P., Hawkins, S., Gray, O., Evason, E. and Whittington, D. (2005) A primary care-based needs assessment of people with multiple sclerosis, *The British Journal of General Practice: The Journal of the Royal College of General Practitioners*, 55(514), pp. 378–383.

Mager, B. (2008) Service Design, In Erlhoff, M. and Marshall, T. (eds.), *Design Dictionary: Perspectives on Design Terminology*, Basel, Birkhäuser, pp. 354–356.

Mäki, U. (2013) Performativity: Saving Austin from MacKenzie, In Karakostas, V. and Dieks, D. (eds.), *EPSA11 Perspectives and Foundational Problems in Philosophy of Science*, Springer International Publishing, pp. 443–453, [online] Available at: http://link.springer.com/10.1007/978-3-319-01306-0 (Accessed 22 March 2016).

Malpass, M. (2013) Between Wit and Reason: Defining Associative, Speculative, and Critical Design in Practice, *Design and Culture*, 5(3), pp. 333–356.

Martin, G. P. (2008) 'Ordinary people only': knowledge, representativeness, and the publics of public participation in healthcare, Sociology of Health & Illness, 30(1), pp. 35–54.

Martin, G. P., Carter, P. and Dent, M. (2018) Major health service transformation and the public voice: conflict, challenge or complicity?, Journal of Health Services Research & Policy, 23(1), pp. 28–35.

Mattelmäki, T. (2006) *Design probes*, Helsinki, University of Art and Design.

Mattlemäki, T. (2002) Empathy Probes, In Binder, T., Computer Professionals for Social Responsibility, and Battarbee, K. (eds.), *Proceedings of the Participation Design Conference: Malmö, Sweden, 23 - 25 June*, 2002, Palo Alto, Calif, Computer Professionals for Social Responsibility.

Mays, N. and Pope, C. (1996) Rigour in qualitative research, In Mays, Nicholas and Pope, Catherine (eds.), *Qualitative research in health care*, London, BMJ Books.

Mazanderani, F., Kelly, J. and Ducey, A. (2018) From embodied risk to embodying hope: Therapeutic experimentation and experiential information sharing in a contested intervention for Multiple Sclerosis, *BioSocieties*, 13(1), pp. 232–254.

Mazanderani, F., O'Neill, B. and Powell, J. (2013) 'People power' or 'pester power'? YouTube as a forum for the generation of evidence and patient advocacy, *Patient Education and Counseling*, 93(3), pp. 420–425.

Mazanderani, F. and Paparini, S. (2015) The stories we tell: Qualitative research interviews, talking technologies and the 'normalisation' of life with HIV, *Social Science & Medicine*, 131, pp. 66–73.

McKevitt, C. (2013) Experience, knowledge and evidence: a comparison of research relations in health and anthropology, *Evidence & Policy: A Journal of Research, Debate and Practice*, 9(1), pp. 113–130.

Merleau-Ponty, M. (1962) *Phenomenology of perception*, London; New York, Routledge.

Michael, M. (2016) *Actor-Network Theory Trials, Trails and Translations.*, London, SAGE Publications.

Michael, M. (2012a) Anecdote, In Lury, C. and Wakeford, N. (eds.), *Inventive methods: the happening of the social, Culture, economy, and the social*, London ; New York, Routledge, pp. 25–35.

Michael, M. (2012b) De-signing the object of sociology: toward an 'idiotic' methodology: De-signing the object of sociology, *The Sociological Review*, 60, pp. 166–183.

Michael, M. (2004) On Making Data Social: Heterogeneity in Sociological Practice, *Qualitative Research*, 4(1), pp. 5–23.

Michael, M. (2011) 'What Are We Busy Doing?': Engaging the Idiot, *Science, Technology & Human Values*, 37(5), pp. 528–554.

Moggridge, B. (2007) *Designing interactions*, Cambridge, Mass, MIT Press.

Mol, A. (1998) Missing Links, making links: The performance of some atherosclerosis, In Berg, M. and Mol, A. (eds.), *Differences in medicine: unraveling practices, techniques, and bodies, Body, commodity, text*, Durham, N.C, Duke University Press, pp. 144–165.

Mol, A. (1999) Ontological Politics: A Word and Some Questions, In Law, J. and Hassard, J. (eds.), *Actor network theory and after, The Sociological review monographs*, Oxford [England] ; Malden, MA, Blackwell/Sociological Review.

Mol, A. (2006) Proving or Improving: On Health Care Research as a Form of Self-Reflection, *Qualitative Health Research*, 16(3), pp. 405–414.

Mol, A. (2002) *The body multiple: ontology in medical practice*, Durham, Duke University Press.

Mol, A. and Law, J. (2004) Embodied Action, Enacted Bodies: the Example of Hypoglycaemia, *Body & Society*, 10(2–3), pp. 43–62.

Mol, A. and Law, J. (2001) Situated Bodies and Distributed Selves: on Doing Hypoglycaemia., In *Bodies on Trial: Performances and Politics in Medicine and Biology*, pp. 1–12.

Morse, J. M. (ed.) (1991) *Qualitative nursing research: a contemporary dialogue*, Rev. ed, Newbury Park, Calif, Sage Publications.

Moser, I. (2000) Against Normalisation: Subverting Norms of Ability and Disability, *Science as Culture*, 9(2), pp. 201–240.

Moser, I. (2006) Disability and the promises of technology: Technology, subjectivity and embodiment within an order of the normal, *Information, Communication & Society*, 9(3), pp. 373–395.

Moser, I. and Law, J. (2003) Making Voices: New Media Technologies, Disabilities, and Articulation, In Liestøl, G., Morrison, A., and Rasmussen, T. (eds.), *Digital Media Revisited: Theoretical and Conceptual Innovation in Digital Domains*, Cambridge, Mass., London, pp. 491–520.

MS Society (2015) What is MS?, *MS Society*, Charity, [online] Available at: http://www.mssociety.org.uk/what-is-ms (Accessed 17 September 2015).

Neves, S. M. P. das (2014) *Enhancing the post-stroke patient experience at mealtime through participatory design: Eliciting, connecting and supporting multi-voicedness*. PhD Thesis, Glasgow, The Glasgow School of Art.

Nguyen, V.-K. (2013) Counselling against HIV in Africa: a genealogy of confessional technologies, *Culture, Health & Sexuality*, 15(sup4), pp. 440–452.

Nguyen, V.-K., Appadurai, A., Comaroff, J. L. and Farquhar, J. (2010) *Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*, Durham, Duke University Press.

NICE (2012) *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services*, National Institute for Health and Clinical Excellence, [online] Available at: http://www.nice.org.uk/guidance/cg138 (Accessed 13 September 2014).

Niedderer, K. (2007) Designing Mindful Interaction: The Category of Performative Object, *Design Issues*, 23(1), pp. 3–17.

Nordgren, L. (2008) The performativity of the service management discourse: 'value creating customers' in health care, *Journal of Health Organization and Management*, 22(5), pp. 510–528.

Norman, D. A. and Drapper (1986) *The design of everyday things*, Hillsdale, N.J, Erlbaum.

Nortvedt, M. W., Riise, T., Myhr, K.-M. and Nyland, H. I. (2000) Performance of the SF-36, SF-12, and RAND-36 Summary Scales in a Multiple Sclerosis Population, *Medical Care*, 38(10), [online] Available at: https://journals.lww.com/lww-medicalcare/Fulltext/2000/10000/Performance_of_the_SF_36,_SF_12,_and_RAND_36.6.aspx (Accessed 1 February 2014).

Nurse-Patient Relations and Benner, P. E. (eds.) (1994) *Interpretive phenomenology: embodiment, caring, and ethics in health and illness*, Thousand Oaks, Calif, Sage Publications.

Oliver, M. (1990) The Politics of Disablement, London, Macmillan Education UK, [online] Available at: http://link.springer.com/10.1007/978-1-349-20895-1 (Accessed 5 March 2019).

Osborne, L. A., Middleton, R. M., Jones, K. H., Ford, D. V. and Noble, J. G. (2013) Desirability and expectations of the UK MS Register: Views of people with MS, *International*

Journal of Medical Informatics, 82(11), pp. 1104–1110.

Osborne, T. and Rose, N. (1999) Do the social sciences create phenomena?: the example of public opinion research, *The British Journal of Sociology*, 50(3), pp. 367–396.

Pardini, M., Cutter, G. and Sormani, M. P. (2017) Clinical trial design for progressive MS trials, *Multiple Sclerosis Journal*, 23(12), pp. 1642–1648.

Penta, M., Thonnard, J. L. and Tesio, L. (1998) ABILHAND: a Rasch-built measure of manual ability, *Archives of Physical Medicine and Rehabilitation*, 79(9), pp. 1038–1042.

Pfennings, L. E. M. A., Ploeg, H. M., Cohen, L., Bramsen, I., Polman, C. H., Lankhorst, G. J. and Vleugels, L. (2009) A health-related quality of life questionnaire for multiple sclerosis Patients, *Acta Neurologica Scandinavica*, 100(3), pp. 148–155.

Pickering, A. (1995) *The mangle of practice: time, agency, and science*, Chicago, University of Chicago Press.

Pine, B. J. and Gilmore, J. H. (1999) *The experience economy: work is theatre & every business a stage*, Boston, Harvard Business School Press.

Platz, T. (ed.) (2005) ARM - Arm rehabilitation measurement: manual for performance and scoring of the Fugl-Meyer test (arm section), *Action Research Arm test and the Box-and-Block test*. Aufl, Baden-Baden, Dt. Wiss.-Verl. (DWV).

PMCPA (2016) *Code of practice for the pharmaceutical industry*, [online] Available at: https://www.abpi.org.uk/media/1605/code_of_practice_2016.pdf (Accessed 11 September 2018).

Pols, J. (2005) Enacting appreciations: beyond the patient perspective, *Health care analysis: journal of health philosophy and policy*, 13(3), pp. 203–221.

Pols, J. (2014) Knowing Patients: Turning Patient Knowledge into Science, *Science, Technology, & Human Values*, 39(1), pp. 73–97.

Prahalad, C. K. and Ramaswamy, V. (2004) Co-creation experiences: The next practice in value creation, *Journal of Interactive Marketing*, 18(3), pp. 5–14.

Puig de la Bellacasa, M. (2011) Matters of care in technoscience: Assembling neglected things, *Social Studies of Science*, 41(1), pp. 85–106.

Puig de la Bellacasa, M. (2017) *Matters of care: speculative ethics in more than human worlds*, Posthumanities, Minneapolis, University of Minnesota Press.

Pullin, G. (2013) *17 ways to say yes, exploring nuanced tone of voice in augmentative communication and designing new interactions with speech synthesis*. PhD Thesis, Dundee, University of Dundee, [online] Available at: https://www.dundee.ac.uk/djcad/staff/profile/graham-pullin.php#tab-Researchoutputs.

Pullin, G. (2009) *Design meets disability*, Cambridge, Mass, MIT Press.

Rabeharisoa, V., Moreira, T. and Akrich, M. (2014) Evidence-based activism: Patients', users' and activists' groups in knowledge society, BioSocieties, 9(2), pp. 111–128.

Räsänen, M. and Nyce, J. M. (2013) The Raw is Cooked: Data in Intelligence Practice, *Science, Technology & Human Values*, [online] Available at: http://sth.sagepub.com/content/early/2013/04/15/0162243913480049 (Accessed 15 April 2016).

Reeves, R., West, E. and Barron, D. (2013) Facilitated patient experience feedback can improve nursing care: a pilot study for a phase III cluster randomised controlled trial, *BMC Health Services Research*, 13(1), [online] Available at: http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-13-259 (Accessed 17 October 2018).

Reiners, G. (2012) Understanding the Differences between Husserl's (Descriptive) and Heidegger's (Interpretive) Phenomenological Research, *Journal of Nursing & Care*, 01(05), [online] Available at: http://dx.doi.org/10.4172/2167-1168.1000119 (Accessed 8 April 2016).

Renedo, A. and Marston, C. (2011) Healthcare professionals' representations of 'patient and public involvement' and creation of 'public participant' identities: Implications for the development of inclusive and bottom-up community participation initiatives, *Journal of Community & Applied Social Psychology*, 21(3), pp. 268–280.

Riazi, A. (2006) Patient-reported Outcome Measures in Multiple Sclerosis, *International MS journal / MS Forum*, 13(3), pp. 92–99.

Ritvo, P., Fischer, J., Miller, D., Andrews, H., Paty, D. and LaRocca, N. (1997) *Multiple Sclerosis Quality of Life Inventory: A User's Manual*, New York, NY, National Multiple Sclerosis Society.

Robert, G. (2013) Participatory action research: using experience-based co-design to improve the quality of healthcare services, In Ziebland, S., Coulter, A., Calabrese, J. D., and Locock, L. (eds.), *Understanding and Using Health Experiences, Oxford University Press*, pp. 138–149.

Roche (2018) *Floodlight Open. Understanding MS together. The power to make the invisible is in your hands*, [online] Available at: https://www.floodlightopen.com/en-US/ (Accessed 19 September 2018).

Rodgers, P. and Yee, J. (2016) Design Research is Alive and Kicking..., In *DRS2016 - Design Research Society 50th Anniversary Conference*, Brighton, UK.

Romberg, A., Ikonen, A., Ruutiainen, J., Virtanen, A. and Hämäläinen, P. (2012) The effects of heat stress on physical functioning in persons with multiple sclerosis, *Journal of the Neurological Sciences*, 319(1–2), pp. 42–46.

Royal Society (ed.) (1985) *The public understanding of science*, London.

Ruppert, E. (2011) Population Objects: Interpassive Subjects, *Sociology*, 45(2), pp. 218–233.

Ruppert, E., Law, J. and Savage, M. (2013) Reassembling Social Science Methods: The

Challenge of Digital Devices, *Theory, Culture & Society*, 30(4), pp. 22–46.

Salih, S. (2007) On Judith Butler and Performantivity, In Lovaas, K. and Jenkins, M. M. (eds.), *Sexualities & communication in everyday life: a reader*, Thousand Oaks, Calif, SAGE Publications.

Salvador, T., Bell, G. and Anderson, K. (2010) Design Ethnography, *Design Management Journal*, 10(4), pp. 35–41.

Sanders, E. B.-N. and Stappers, P. J. (2008) Co-creation and the new landscapes of design, *CoDesign*, 4(1), pp. 5–18.

Scanlon, L. (2013) PatientsLikeMe Unveils New Tool to Match Patients With Clinical Trials Worldwide, *Marketwired*, [online] Available at: http://www.marketwired.com/press-release/patientslikeme-unveils-new-tool-to-match-patients-with-clinical-trials-worldwide-1767363.htm.

Schön, D. A. (1983) The reflective practitioner: how professionals think in action, New York, Basic Books.

Schuler, D. and Namioka, A. (eds.) (1993) *Participatory design: principles and practices*, Hillsdale, N.J, L. Erlbaum Associates.

Searle, J. R. (2008) *Philosophy in a New Century: Selected Essays*, Cambridge, Cambridge University Press, [online] Available at: http://ebooks.cambridge.org/ref/id/CBO9780511812859 (Accessed 9 July 2015).

Sethi, V., Yousry, T., Tozer, D., Muhlert, N., Ron, M., Golay, X., Wheeler-Kingshott, C., Miller, D., Chard, D. and Altmann, D. (2013) Does the lobar distribution of cortical grey matter (CGM) lesions correlate with cognitive impairment seen in multiple sclerosis patients?, In *Proceedings for ECTRIMS 2013. October 2-5, 2013*, Copenhagen, Denmark.

Sevaldson, B. (2010) Discussions & Movements in Design Research, *FOR Makademisk*, 3(1), [online] Available at: https://journals.hioa.no/index.php/formakademisk/article/view/137 (Accessed 3 November 2016).

Shakespeare, T. and Watson, N. (2001) The social model of disability: An outdated ideology?, In Research in Social Science and Disability, Bingley, Emerald (MCB UP), pp. 9–28.

Shapin, S. and Schaffer, S. (1985) *Leviathan and the air-pump: Hobbes, Boyle, and the experimental life: including a translation of Thomas Hobbes, Dialogus physicus de natura aeris by Simon Schaffer*, Princeton, N.J, Princeton University Press.

Sharrack, B. and Hughes, R. A. (1997) Reliability of distance estimation by doctors and patients: cross sectional study, *BMJ*, 315(7123), pp. 1652–1654.

Sharrack, B., Hughes, R. A., Soudain, S. and Dunn, G. (1999) The psychometric properties of clinical rating scales used in multiple sclerosis, *Brain: A Journal of Neurology*, 122 (Pt 1),

pp. 141–159.

Shedroff, N. (2001) *Experience design 1.1*, New Riders.

Shostack, G. L. (1984) Designing Services That Deliver, *Harvard Business Review*, [online] Available at: https://hbr.org/1984/01/designing-services-that-deliver (Accessed 8 August 2016).

Singleton, V. (1998) Stabilising instabilities:the role of the laboratory in the UK cervical screening programme, In Berg, M. and Mol, A. (eds.), *Differences in medicine: unraveling practices, techniques, and bodies*, Durham, N.C, Duke University Press, pp. 86–104.

Singleton, V. and Michael, M. (1993) Actor-Networks and Ambivalence: General Practitioners in the UK Cervical Screening Programme, *Social Studies of Science*, 23(2), pp. 227–264.

Smeenk, W., Sturm, J. and Eggen, B. (2018) Empathic handover: how would you feel? Handing over dementia experiences and feelings in empathic co-design, *CoDesign*, 14(4), pp. 259–274.

Smith, P. (1992) *The emotional labour of nursing: its impact on interpersonal relations, management and the educational environment in nursing*, Repr, Houndmills, Basingstoke, MacMillan.

Speed, E., Davison, C. and Gunnell, C. (2016) The anonymity paradox in patient engagement: reputation, risk and web-based public feedback: Table 1, *Medical Humanities*, 42(2), pp. 135–140.

Springgay, S. and Truman, S. E. (2017) A Transmaterial Approach to Walking Methodologies: Embodiment, Affect, and a Sonic Art Performance, *Body & Society*, 23(4), pp. 27–58.

Star, S. L. (ed.) (1995) *Ecologies of knowledge: work and politics in science and technology, SUNY series in science, technology, and society*, Albany, State University of New York Press.

Star, S. L. (1990) Power, technology and the phenomenology of conventions: on being allergic to onions, *The Sociological Review*, 38(S1), pp. 26–56.

Star, S. L. (1983) Simplification in Scientific Work: An Example from Neuroscience Research, *Social Studies of Science*, 13(2), pp. 205–228.

Star, S. L. (1999) The Ethnography of Infrastructure, *American Behavioral Scientist*, 43(3), pp. 377–391.

Star, S. L. and Griesemer, J. R. (1989) Institutional Ecology, `Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39, *Social Studies of Science*, 19(3), pp. 387–420.

Star, S. L. and Strauss, A. (1999) Layers of Silence, Arenas of Voice: The Ecology of Visible

and Invisible Work, *Computer Supported Cooperative Work (CSCW)*, 8(1–2), pp. 9–30.

Stengers, I. (2018) *Another science is possible: a manifesto for slow science*, English edition, Cambridge ; Medford, MA, Polity.

Stengers, I. (2005) The cosmopolitical proposal, *Making things public: Atmospheres of democracy,* pp. 994–1003.

Stengers, I. (2000) *The invention of modern science, Theory out of bounds*, Minneapolis, University of Minnesota Press.

Stengers, I. (2002) *In Hope: new philosophies for change*, Annandale, Pluto Press, pp. 244–273.

Strandvad, S. and Pedersen, K. (2015) Co-Producing a Festival Experience: A Socio-Material understanding of Experience Design, In Benz, P. (ed.), *Experience design: concepts and case studies*, London ; New York, Bloomsbury Academic, pp. 105–112.

Strauss, A. L. (1975) Chronic illness and the quality of life, Saint Louis, Mosby.

Suchman, L. (2007) *Human-machine reconfigurations: plans and situated actions*, 2nd ed, Cambridge ; New York, Cambridge University Press.

Suchman, L. (1995) Making work visible, *Communications of the ACM*, 38(9), p. 56-ff.

Suchman, L., Trigg, R. and Blomberg, J. (2002a) Working artefacts: ethnomethods of the prototype, *British Journal of Sociology*, 53(2), pp. 163–179.

Suchman, L., Trigg, R. and Blomberg, J. (2002b) Working artefacts: ethnomethods of the prototype, *British Journal of Sociology*, 53(2), pp. 163–179.

Sullivan, M. (2003) The new subjective medicine: taking the patient's point of view on health care and health, *Social Science & Medicine*, 56(7), pp. 1595–1604.

Suri, J. F. and Howard, S. G. (2006) Going Deeper, Seeing Further: Enhancing Ethnographic Interpretations to Reveal More Meaningful Opportunities for Design, *Journal of Advertising Research*, 46(3), pp. 246–250.

Suri, J. F. and IDEO (eds.) (2015) *The little book of design research ethics*, London, IDEO.

Svabo, C. and Shanks, M. (2015) Experience as Excursion: A Note towards a Metaphysics of Design Thinking, In Benz, P. (ed.), *Experience Design: Concepts and Case Studies*, London, Bloomsbury Academic, pp. 23–32.

Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P., Robson, R., Thabane, M., Giangregorio, L. and Goldsmith, C. H. (2010) A tutorial on pilot studies: the what, why and how, *BMC Medical Research Methodology,* 10(1), [online] Available at: http://bmcmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-10-1 (Accessed 17 October 2018).

Thomson, A. (2014) Barts MS Advisory Group, *Barts MS Research Blog*, Blog, [online] Available at: http://multiple-sclerosis-research.blogspot.com/p/barts-ms-advisory-group.html (Accessed 17 October 2018).

Thomson, A., Carol Rivas, Tosh Denholm and Gavin Giovannoni (2013) Multiple sclerosis (MS) Outpatient Future Groups: Designing tools of interaction in health service improvement activities, In Alaster Yoxall and Kirsty Christer (eds.), *Proceedings of the Second European Conference on Design 4 Health 2013, 3 - 5 July 2013*, Sheffield UK, Sheffield Hallam University, Art & Design Research Centre, Sheffield, UK.

Thomson, A., Davis, A., Paterson, A., Giovannoni, G. and Schmierer, K. (2015) Designing an information resource to explain diagnostic lumbar puncture and promote best practice, In *Association of British Neurologists Annual Meeting, Harrogate*.

Thomson, A., Espasandin, M., Denholm, T. and Giovannoni, G. (2011) Analysing and redesigning the outpatient experience for people with multiple sclerosis, In *5th Joint triennial congress of the European and Americas Committees for Treatment and Research in Multiple Sclerosis, 3-5 October 2011*, Amsterdam, The Netherlands.

Thomson, A., Rivas, C. and Giovannoni, G. (2015) Multiple sclerosis outpatient future groups: improving the quality of participant interaction and ideation tools within service improvement activities, *BMC Health Services Research*, 15(1).

Timmermans, S. and Berg, M. (1997) Standardization in Action: Achieving Local Universality through Medical Protocols, *Social Studies of Science*, 27(2), pp. 273–305.

U.S. Department of Health and Human Services and Food and Drug Administration (2009) *Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims*, [online] Available at: http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf Accessed August 27, 2014.

Varela, F. (1999) The specious present: A neurophenomenology of time consciousness, In Petitot, J., Varela, F. J., Pacoud, B., and Roy, J.-M. (eds.), *Naturalizing Phenomenology*, Stanford University Press, pp. 266--314.

Vennik, F. D., Adams, S. A., Faber, M. J. and Putters, K. (2014) Expert and experiential knowledge in the same place: Patients' experiences with online communities connecting patients and health professionals, *Patient Education and Counseling*, 95(2), pp. 265–270.

Vickrey, B. G., Hays, R. D., Harooni, R., Myers, L. W. and Ellison, G. W. (1995) A health-related quality of life measure for multiple sclerosis, *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 4(3), pp. 187–206.

Walters, A. J. (1995) The phenomenological movement: implications for nursing research, *Journal of Advanced Nursing*, 22(4), pp. 791–799.

Walton, M. K., Powers, J. H., Hobart, J., Patrick, D., Marquis, P., Vamvakas, S., Isaac, M., Molsen, E., Cano, S., Burke, L. B. and International Society for Pharmacoeconomics and

Outcomes Research Task Force for Clinical Outcomes Assessment (2015) Clinical Outcome Assessments: Conceptual Foundation-Report of the ISPOR Clinical Outcomes Assessment - Emerging Good Practices for Outcomes Research Task Force, *Value in Health: The Journal of the International Society for Pharmacoeconomics and Outcomes Research*, 18(6), pp. 741–752.

Wendt, T. (2015) *Design for Dasein: understanding the design of experiences*, Charleston, SC, Createspace.

West, J., Davey, G., Norris, B., Myerson, J., Anderson, O. and Brodie, A. (2014) Designing out Medical Error: An Interdisciplinary Approach to the Design of Healthcare Equipment, *The Design Journal*, 17(2), pp. 238–266.

Wetherly, L. and Erez, R. (2018) *PIP: a step too far. The impact of the 20 meter rule on people with MS*, MS Society.

Wherton, J., Sugarhood, P., Procter, R., Rouncefield, M., Dewsbury, G., Hinder, S. and Greenhalgh, T. (2012) Designing assisted living technologies 'in the wild': preliminary experiences with cultural probe methodology, *BMC Medical Research Methodology*, 12(1), p. 188.

White, J., Kieseier, B., Newsome, S., Zhu, Y., Cui, Y., Seddighzadeh, A., Hung, S., Deykin, A. and Subramanyam, M. (2013) Immunogenicity with peginterferon beta-1a in patients with relapsing-remitting multiple sclerosis: data from the pivotal phase 3 ADVANCE study, In *Proceedings for ECTRIMS 2013. October 2-5, 2013*, Copenhagen, Denmark.

Whitehead, A. N. (1978) *Process and Reality: Corrected Edition*, Griffin, D. R. and Sherburne, D. (eds.), New York, Free Press [originally published in 1929].

Wiener, C. L. (2000) *The elusive quest: accountability in hospitals, Social problems and social issues*, New York, Aldine de Gruyter.

Wilkie, A. (2013) Prototyping as Event: Designing the Future of Obesity, *Journal of Cultural Economy*, 7(4), pp. 476–492.

Wilkie, A. (2010) *User Assemblages in Design: An Ethnographic Study*. PhD Thesis, London, Goldsmiths, University of London.

Wilkie, A. and Michael, M. (2009) Expectation and Mobilisation: Enacting Future Users, *Science, Technology & Human Values*, 34(4), pp. 502–522.

Wilkie, A., Michael, M. and Plummer-Fernandez, M. (2015) Speculative method and Twitter: Bots, energy and three conceptual characters: Speculative method and Twitter: Bots, energy and three conceptual characters, *The Sociological Review*, pp. 79–101.

Williams, S. J. (1999) Is anybody there? Critical realism, chronic illness and the disability debate, Sociology of Health and Illness, 21(6), pp. 797–819.

Wilsdon, J., Willis, R. and Demos (Organization: London, E. (2004) *See-through science: why public engagement needs to move upstream*, London, Demos.

Winner, L. (1993) Upon Opening the Black Box and Finding It Empty: Social Constructivism and the Philosophy of Technology, *Science, Technology & Human Values*, 18(3), pp. 362–378.

Winthereik, B. R., van der Ploeg, I. and Berg, M. (2007) The Electronic Patient Record as a Meaningful Audit Tool:Accountability and Autonomy in General Practitioner Work, *Science, Technology, & Human Values*, 32(1), pp. 6–25.

Wolf, J., Niederhauser, V., Marshburn, D. and LaVela, S. (2014) Defining Patient Experience, *Patient Experience Journal*, 1(1), [online] Available at: http://pxjournal.org/cgi/viewcontent.cgi?article=1004&context=journal.

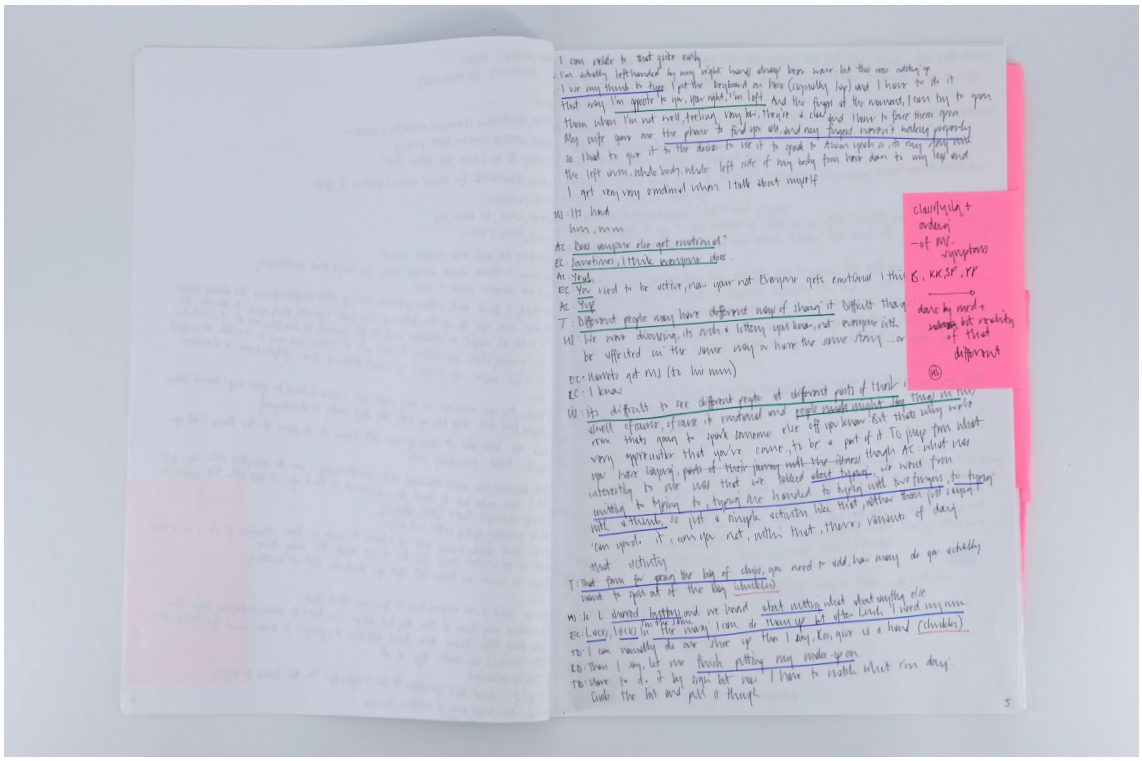
Woolgar, S. (ed.) (1988) *Knowledge and Reflexivity*, London, SAGE Publications.

Wynne, B. (1995) Public Understanding of Science, In *Handbook of Science and Technology Studies*, California, SAGE Publications, pp. 361–388, [online] Available at: http://knowledge.sagepub.com/view/handbook-of-science-and-technology-studies/n17.xml (Accessed 17 September 2015).

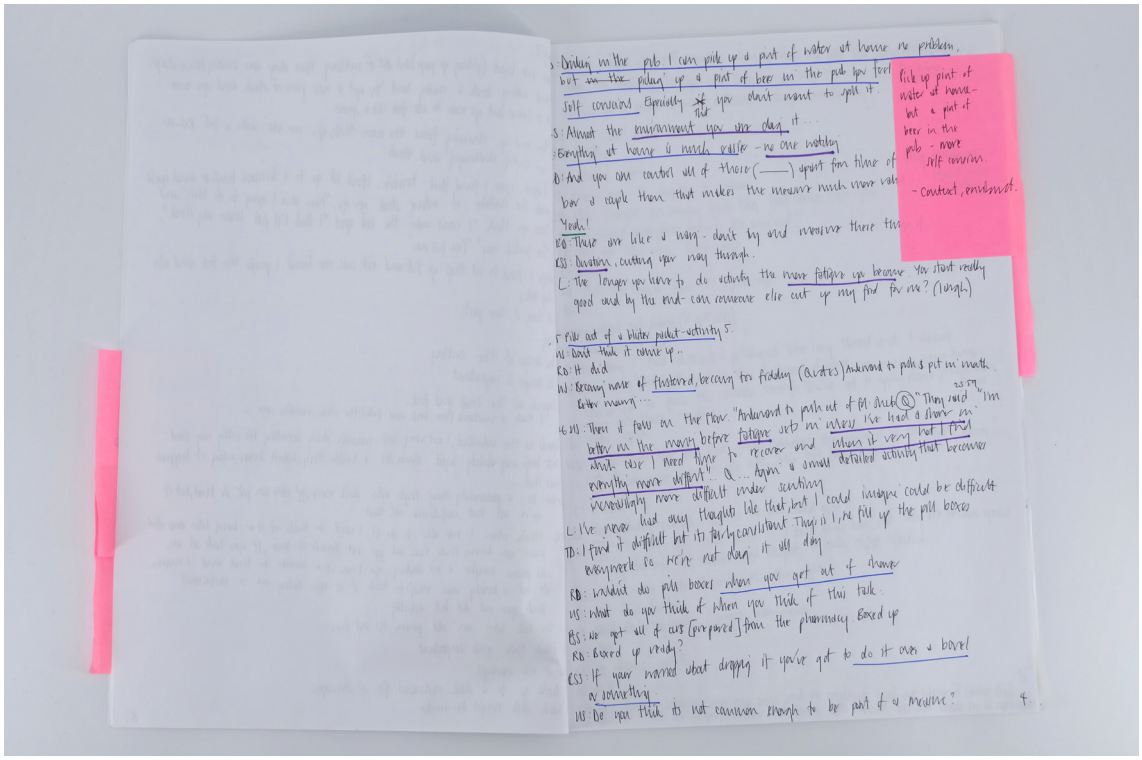
Yaneva, A. (2009) Making the Social Hold: Towards an Actor-Network Theory of Design, *Design and Culture*, 1(3), pp. 273–288.

Zimmerman, J., Stolterman, E. and Forlizzi, J. (2010) An Analysis and Critique of Research Through Design: towards a formalization of a research approach, In *DIS 2010 - Proceedings of the 8th ACM Conference on Designing Interactive Systems*, Aarhus, ACM.

Appendix A: MOT sound recording transcripts



classifying + ordering of MS symptoms
E, KK, SF, RP
done by ward + not reliably of that different



Pick up pint of water at home - not a pint of beer in the pub - more self conscious
- context, environment

Appendix B: Notes from clinic observations

Friday

At about this point I met with Central Appointments to discuss having extra inserts sent out with the appointment letters.

- I met with [redacted] from central appointments and she introduced me to the managers in each team who are very nice and pleasant when explaining the service. The first [redacted] explains how the [redacted] referral system works, then the next [redacted] explains the cell system.

- I then meet the man and the machine who does all the printing.

- When I speak again to the manager again I thank her for letting me meet her team. She said something along the lines of "I wish everyone could come and see the team"

16th April 2013.

1.40pm (pt, friend, nurse, Dr, researcher)

1st pt -

Dr was finishing a sandwich & crisps at desk.

Pt. has no notes so there are temporary folder.

Dr & nurse spend a few minutes flicking through "rather than clinical notes, click on computer to find nurses notes she wrote."

So much for new technology

"Few days storage had been changed"

"I wish I had printed my notes out". - "no spare paper"

- Introduces me "like the one at Homerton we gave you steroids in Feb."
- Bad opening "implies"
- but carries off well enough for a little deception of sperm
- Nurse apology for not printing notes out, talking about changing systems.
- Dr reading letter on screen while pt. talking
- Nurse saying "Do you know why I did that"

Dr "I've also got the useful letter from hospice here and then [illegible] from the researcher both."

Pt "I'm fatigued with needing opioids. Year quite unstable overall year. Yeah"

① expected this. how this created a situation for design?

↓ pressure of gathering data impacting on how data collected in clinic

② - when sitting with pt 2 - you can hear the Nurse talking about her to the medical students.

→ staff nurse approaches me and asks about me, how I am doing, how the project finished?

"I did a very good job."

Dr clinic as a data gathering site.

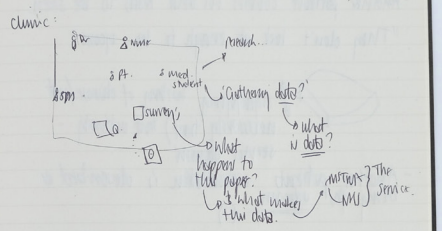
① - expected that to happen. 6 month follow up
- short consultation to get a check up

② not - drops Ben very well (olive oil) chat
- didn't put examination in original pre.

"Talking about research in the clinic
- "you could use your stem cells and I could grow you a new eye!"
- "what was that research they were talking about?"
"I thought they could do eye transplants?"

"Talk about recording by progony. (sounds like sci-fi) people running & against about for money" drop grab of bottle red bag

- Not so much about the technique but about what it made happen.
- Dr comes out later with the second part of pic for the second patient.
- sitting in the waiting room you can clearly hear staff discussing patients in the consultation room.



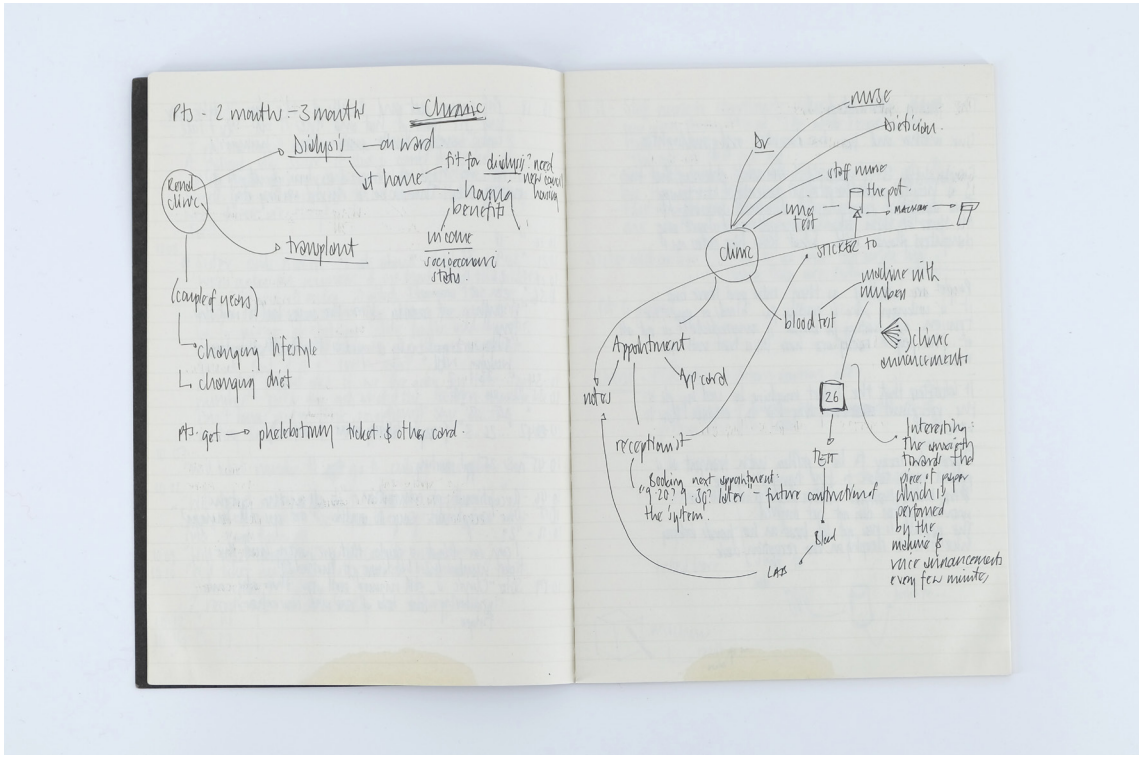
- Research nurse comes over with a patients notes...

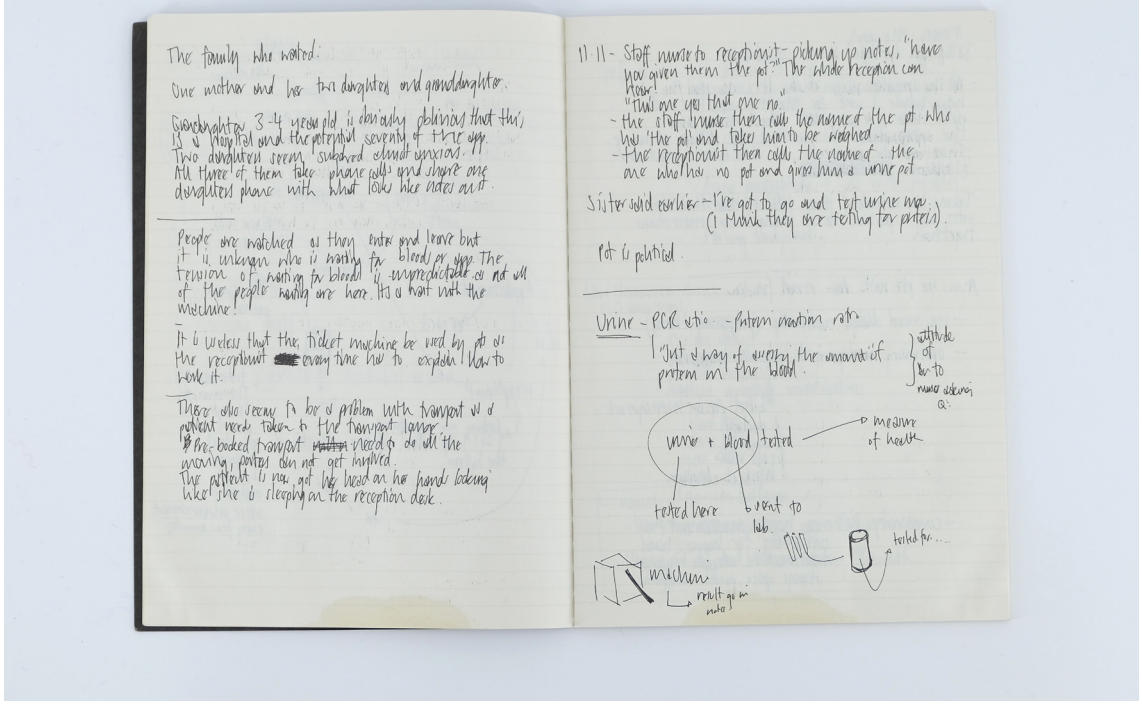
↓ Patients coming from trials unit

"Is it still my patient?"

Dr [redacted] wheelchair in the waiting room...

"all these things add up"




The family who waited:

One mother and her two daughters and granddaughter.

Granddaughter 3-4 years old is obviously oblivious that this is a hospital and the atmosphere severely affected.
Two daughters seem subdued almost anxious.
All three of them take phone calls and ignore one daughters phone with what looks like notes on it.

People are watched as they enter and leave but it is unknown who is waiting for blood or urine. The tension of waiting for blood is unpredictable as not all of the people waiting are here. It's a wait with the machine.

It is useless that the ticket machine be used by get as the receptionist [redacted] every time has to explain how to work it.

Those who seem to be a problem with transport as a patient needs taken to the transport lounge.
Pre-booked transport ~~within~~ needed to do all the morning, patients often not get informed.
The patient is not got her head on her hands looking like she is sleeping on the reception desk.

11.11 - Staff nurse to receptionist - picking up notes, "have you given them the pot?" The white receptionist com back "this one yes that one no"
- the staff nurse then calls the name of the pot who has 'the pot' and takes them to be weighed
- the receptionist then calls the name of the one who has no pot and gives him a urine pot

Sister called earlier - I've got to go and test urine now. (I think they are testing for protein).

Pot is patriotic.

Urine - PCR etc. - protein creation rate

"just a way of assessing the amount of protein in the blood."

attitude of doctor to nurses observations.

Appendix C: MOT study protocol

Barts Health NHS Trust

Queen Mary University of London

Non-CTIMP: Measurement on Our Terms: exploring the role of patients when developing an upper limb Patient Reported Outcome Measurement for Multiple Sclerosis

Short Title/Acronym	Measurement on Our Terms (MOT)
Sponsor	Queen Mary University of London Dr Sally Burtles, Director of Research Services & Business Development Joint Research Management Office Queen Mary Innovation Centre 5 Walden Street London, E1 2EF 020 7882 7260 sponsorsrep@bartshealth.nhs.uk
REC Reference	17/LO/1684
IRAS Project ID	228062

Chief and Principle Investigator:

Alison Thomson
Lecturer in Public Engagement and Patient Public Involvement
Centre for Neuroscience and Trauma
The Blizard Institute
Barts and The London School of Medicine and Dentistry
64 Turner Street
London, E1 2AB

020 7882 2367

a.thomson@qmul.ac.uk

Co-Investigator:

Gavin Giovannoni
Professor of Neurology
Blizard Institute, Centre for Neuroscience and Trauma
QMUL
g.giovannoni@qmul.ac.uk

Carol Rivas
Senior Researcher (Associate Professor)
Social Science Research Unit
UCL
c.rivas@ucl.ac.uk

List of sites:

Participant Identification Centre:
Royal London Hospital
Barts Health NHS Trust

Site:
Camden Society have provided a letter to confirm they are happy for the Unity Café to be used as a research site.
Unity Kitchen Café
Queen Elizabeth Olympic Park,
1A Honour Lea Ave, London E20 1DY

Technical Department:
Centre for Neuroscience and Trauma
Blizard Institute
4 Newark Street
Whitechapel, E1 2AT

Table of Contents

GLOSSARY OF TERMS AND ABBREVIATIONS

DMT	Disease Modifying Therapy
EDSS	Expanded Disability Status Scale
FDA	Food and Drug Administration
c9HPT	Cardboard Nine Hole Peg Test
MS	Multiple Sclerosis
Participant	An individual who takes part in a study
PF	A person with MS who is also a professional facilitator
PPI	Patient Public Involvement
PI	Principle Investigator
PROM	Patient Reported Outcome Measure
PwMS	Person with MS
QMUL	Queen Mary University London
QR	Qualitative Researcher
9HPT	Nine Hole Peg Test
WebEDSS	Web-based Expanded Disability Status Scale

SIGNATURE PAGE

Chief Investigator Agreement

The clinical study as detailed within this research protocol **(Version 0.5, dated 12th September 2017)**, or any subsequent amendments will be conducted in accordance with the Research Governance Framework for Health & Social Care (2005), the World Medical Association Declaration of Helsinki (1996) and the current applicable regulatory requirements and any subsequent amendments of the appropriate regulations.

Chief Investigator Name: Alison Thomson
Chief Investigator Site: Blizard Institute, Queen Mary, University of London

Signature and Date:

Principal Investigator Agreement *(if different from Chief investigator)*

The clinical study as detailed within this research protocol **(Version 0.5, dated 12th September 2017)**, or any subsequent amendments will be conducted in accordance with the Research Governance Framework for Health & Social Care (2005), the World Medical Association Declaration of Helsinki (1996) and the current applicable regulatory requirements and any subsequent amendments of the appropriate regulations.

Principal Investigator Name: Alison Thomson
Principal Investigator Site: Blizard Institute, Queen Mary, University of London

Signature and Date:

SUMMARY

Short Title	Measurement on Our Terms: exploring the role of patients when developing an upper limb Patient Reported Outcome Measurement (PROM) for Multiple Sclerosis (MS)
Research Sites	1. Participant Identification CentreRoyal London Hospital Outpatient Department part of Barts Health NHS Trust 2. Site: Utility Kitchen Cafe in the Queen Elizabeth Olympic Park 3. Technical Department: The Blizard Institute, Queen Mary University of London
Objectives	Primary objective: 1. To develop a PROM to evaluate upper limb function in people with MS Secondary Objective: 2. To explore how patients experiential knowledge can contribute to the development of a PROM
Methodology	This is a mixed method study using three focus groups to identify patient important upper limb activities to develop a PROM specific for people with MS. It has a nested component exploring the impact of experiential knowledge on PROM development and will use descriptive analysis to describe the study participants.
Number of Participants	Three focus groups conducted by a patient facilitator and the researcher consisting of between eight and ten participants. Each participant will attend all three focus groups.
Main Inclusion Criteria	• Be able to give informed consent without assistance • Male and female patients aged 18+ and willing to participate in the study. • All participants will have been diagnosed with multiple sclerosis according to the revised "MacDonald" criteria (Polman et al., 2011) at least 6 months beforehand. • Participants will have an EDSS of 3.5 to 8.0 inclusive as measured through the WebEDSS with identified upper limb function problems • Be able to attend the three focus group sessions in East London and must have the ability to understand and communicate in English. • Have a documented assessment attempt for the cardboard 9-Hole Peg test (c9HPT) prior to focus group

Data analysis	Quantitative data collected in this study will be used for descriptive analysis of the study participants. Immersion/Crystallization will be used to for qualitative data analysis to develop activities for the PROM as well as exploring experiential knowledge of patients during PROM development.
Proposed Start Date	01/10/2017
Proposed End Date	31/05/2018
Study Duration	8 months

1. INTRODUCTION

1.1 BACKGROUND

This study is being led by Alison Thomson, Lecturer in Patient Public Involvement (PPI) and Public Engagement in Science from Queen Mary University of London (QMUL), who has extensive experience involving patients in research activities (Thomson et al., 2011, 2015b, 2015a). Alison established and chairs the Barts MS Patient Advisory Group (a PPI group) and has involved them in the design, conduct and dissemination of this study. The outcome measure being developed through this study is a requirement Alison's professional role at QMUL, while the exploration of patient involvement in this process will form part Alison's PhD thesis registered at Goldsmiths, University of London.

1.1 PATIENT REPORTED OUTCOME MEASURE (PROM)

PROMs are an umbrella term referring to questionnaires, interviews, and other methods of assessing health, illness and benefits of health care from the patient's perspective. From a clinical perspective, PROMs are essentially an evaluation of the meaningfulness of therapeutic effectiveness and management strategies as rated by patients (Smith and Weldring, 2013). PROMs are sometimes referred to as quality of life measures for this reason. For a person with MS (PwMS), PROMS are claimed to measure and capture the direct impact of the chronic illness on the day-to-day lives (Riazi, 2006) as they are completed by patients, as opposed to tests conducted on patients, like MRI scans or examinations.

1.2 UPPER LIMB FUNCTION AND PEOPLE WITH MULTIPLE SCLEROSIS

Multiple Sclerosis (MS) is a chronic progressive disease of the central nervous system (Compston and Coles, 2008) and is the leading cause of non-traumatic disability in young and middle aged adults (Compston, 2005; Pugliatti et al., 2006). It commonly leads to cumulative, heterogeneous mixed disabilities over time, ranging from motor and sensory impairments to fatigue, impaired vision, cognitive deficits, speech and swallowing problems, bladder, bowel and sexual dysfunction. The combination of different symptoms and disabilities often limits a person's ability to perform activities of daily life and social activities which then affect people's quality of life.

Historically, MS treatments have focused on preserving lower limb function – the ability to walk - and this is reflected in three main areas of clinical practice and research. Firstly, within the current climate of disease modifying therapies (DMTs) available to PwMS, none are licensed for

people with advanced forms of MS. Secondly, wheelchair users are excluded from the majority of clinical trials as (i) it is thought to be difficult to measure clinical change in PwMS whose motor functions are already severely affected leading to concern the impact of DMTs is too subtle to detect and (ii) pathophysiological dogma suggests that once a certain level of EDSS is reached, MS becomes a neurodegenerative disease that is not amenable to DMT (Leray et al., 2010). Finally, and related to the second point, the gold standard of disease measurement, the expanded disability status scale (EDSS) (Kurtzke, 1983; Schwid et al., 1997) is weighted towards mobility i.e. a person's ability to walk. Results of a recent study (ASCEND, NCT01416181) highlighted these problems as the primary outcomes of the trial were negative; the EDSS and 25-foot timed foot walk, measures of lower limb function dominated the composite measure. However, the nine hole peg test (9HPT), a measure of upper limb function, was positive; trial participants who received natalizumab showed no loss of upper limb function, confirmed at 12 weeks, compared to participants with secondary progressive MS who received placebo.

The Barts MS Research team based at Queen Mary University of London (QMUL) and Barts Health NHS Trust feel that there now needs to be a shift in focus to re-position the importance of upper limb functions for PwMS. In August 2016 we launched the #ThinkHand campaign to raise awareness and also initiate discussions amongst PwMS, clinicians, charities, pharmaceutical companies, regulators and the general public to realise the importance and work towards generating evidence to license DMTs for advanced MS. As part of this campaign, our team has conducted a number of PPI activities at academic conferences, online and at patient events around this topic. Part of this included an online survey where 88% of PwMS (314 of 360 respondents) described their upper limb function to be more important to them than their lower limb function (Dubuisson et al., submitted for publication). This highlights the importance of upper limb function from the patient perspective and the unique experiential knowledge of living with the condition that PwMS have (Beresford, 2005). This is supported by clinical studies; Bertoni et al. (2015) provide evidence that 75% of PwMS have bilateral impaired manual dexterity even in the early stages of the disease. Arm and hand function, are very important to perform activities of daily living like eating, dressing and grooming (Yozbatiran et al., 2006), and even more so for people who have already lost lower limb function as further loss of functioning contributes to low mood, reduced independence and quality of life. Therefore, it is imperative that treatments are aimed at preserving upper limb function.

1.3 PROMS TO MEASURE UPPER LIMB FUNCTION FOR PEOPLE WITH MULTIPLE SCLEROSIS

As healthcare providers place increasing emphasis on evidence based practice, outcome measures such as the EDSS and quantitative descriptions of patients' disease experience have become more important. Particular emphasis is now placed on including PROMs in trials and clinical practice driven by governing bodies such as the US Food and Drug Administration (FDA)(U.S. Department of Health and Human Services and Food and Drug Administration, 2009), the European Medicine Agency (European Medicines Agency, 2005), and the Department of Health (Department of Health, 2001).

Current PROMs focus on measures of body functions and structures looking at the capacity to assess the maximal ability to execute a task or an action (e.g. the 9HPT is gold standard objective measure for manual dexterity (Fischer et al., 1999)) or an activity performance measure measuring the person's habitual performance of tasks in their normal environment (the ABILHAND).

There are a range of upper limb PROMS in use, but few have been used in MS research and we are aware of only one developed specifically for PwMS (Lamers et al., 2016). For example the ABILHAND was originally developed for rheumatoid arthritis with subsequent versions developed for people with stroke (Penta et al., 1998). Although these have been validated for use with PwMS (Barrett et al., 2013) their transference from another condition poses problems in that the activities that are included lack relevance to the activities specific to living with MS. They also lack relevance to modern living. For example, they are influenced by the ability to walk and there is no mention of urinary catheters, and no mention of new technologies such as the use of touchscreen phones or tablets.

1.4 DEVELOPING A NEW PROM FOR UPPER LIMB FUNCTION IN MS

This study will develop a new PROM to specifically measure upper limb function in people with MS using a more participatory approach to PROM development. This is inspired by participatory research as the study has been designed by PwMS and will involve PwMS with upper limb problems, who are the people whose activities and life worlds are under study (Bergad and Thomas 2012) throughout.

PROMs are typically derived by clinicians and University researchers who only involve patients at specific stages. They therefore embed what these medical and academic professionals believe to be a "good" outcome (Rose et al., 2011), i.e. one that is clinically meaningful from the perspective of the clinicians and the researcher but these outcomes may not be meaningful to

the patients themselves. Jenkins and Morley (2016) describe how the potential for PROMS to be useful for individual patients still remains unresolved. Further, Lamers and Feys (2014) state that a key characteristic of PROMS that has been overlooked in MS is how they can be used to facilitate the evolution of rehabilitation content and strategies. This highlights the need to develop PROMS that include activities that are meaningful to individual patients and can enable them to develop strategies and continue to do these activities.

1.5 PATIENT INVOLVEMENT IN PROM DEVELOPMENT

It is increasingly recognised that PROM development needs to involve patients at more stages. For example, the increasing importance of PPI highlights the key role of patient involvement in healthcare policy (Savory, 2010), service improvement (House of Commons Health Committee, 2007) the democratisation of research (Fals-Borda and Rahman, 1991) and is increasingly recognised as crucial to the development of PROMS (Wicks, 2015). The process of PROM development and the role of both the patient and their experiential knowledge has already been explored in mental health (Rose et al., 2011; Trujols et al., 2013) and there have been a number of patient-generated or patient-led outcome measures developed in the field of Rheumatoid arthritis but not in MS. Classified as "patient-generated" they are developed from the perspective of users, with the involvement of people who have experienced the context of use first hand (Rose et al., 2011). This is done through participatory approaches where these people are involved at all stages of development from item selection, to scale development and testing.

This suggests that effort should be put into developing PROMS that are entirely patient generated so the development process continually captures, incorporates and values the experiential knowledge and perspectives of patients, not just that of the researcher and clinicians (Beresford, 2005; Trujols et al., 2013). Including the people who will be using the end measure in the PROM development process in a participatory way will produce a measure that reflects the needs and experiences of patients and is more likely to improve clinical practice (Kjeken et al., 2010) and produce outcomes of meaning to the patient experience. Further, including these people in this process through face-to-face meetings can reduce power relations between patient and academic researchers, which is the axiom of participatory research (Cornwall and Jewkes, 1995).

2 STUDY OBJECTIVES

2.1 PRIMARY OBJECTIVE

- To develop a PROM to evaluate upper limb function in people with MS

2.2 SECONDARY OBJECTIVE

- To explore how patients experiential knowledge can contribute to the development of a PROM.

2.3 PRIMARY ENDPOINT:

- Produce a draft upper limb outcome measure

2.4 SECONDARY ENDPOINT:

- Develop a list of daily upper limb activities that are affected by people with MS

3 METHODOLOGY

This is a mixed method study consisting of three qualitative focus groups and an online survey. Within the study, there is a nested analysis of the impact of experiential knowledge on the development of a PROM.

3.1 FOCUS GROUPS

This study uses a focus group method to involve patient participants in the PROM development process, similar to the FDA process of item generation, item reduction, measure development and design. The focus group sessions will enable interactions between participants to help with the generation of new ideas and personal reflections based on their experiences of living with MS. The three focus groups will take place over three months with an on-line survey posted after the first focus group to identify topics for the subsequent focus groups. Participants will then discuss the results of the survey and develop categories for a new PROM to measure upper limb function for PwMS.

The focus groups will be led by a professional facilitator (PF) who is also a PwMS supported by the PI. Working together, the PI and PF have extensive experience developing and leading patient sessions. There will also be a qualitative researcher (QR) in each focus group, who is a leader in the field of patient experience and participatory analysis. All researchers will have up to date research governance training.

STUDY SCHEME DIAGRAM

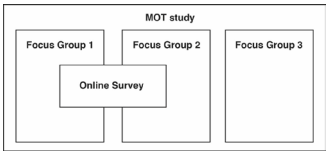


Diagram 1: Demonstrating an overview of the study and how the focus groups and online survey interact

3.1.1 STUDY – RLH AND QUEEN ELIZABETH OLYMPIC PARK, EAST LONDON

The recruitment for the focus groups will be held in the outpatient department of the Royal London Hospital when patients are attending their routine appointments with their MS consultant and MS Nurse.

The focus groups will be held in a community cafe meeting room in the Queen Elizabeth Olympic Park, East London, lasting an average of three hours, led by the PF in conjunction with the PI. They will be held between two and three weeks apart to ensure some memory of the previous discussion and to allow the study to keep up some momentum. This space has been chosen by the Barts MS Patient Advisory group as it is not only has the capacity to hold a meeting with a number of wheelchair users with a taxi drop off space at the entrance but it will provide a safe and respectful environment which is important for focus groups to be held in a

non-medical venue in the belief that this will encourage participants to speak more freely (Kjeken et al., 2010).

3.2 STUDY PARTICIPANT CRITERIA

3.2.1 INCLUSION CRITERIA

Participants will be invited to take part in the focus group sessions if they meet the inclusion criteria of:

- Be able to give informed consent without assistance
- Male and female patients aged 18+ and willing to participate in the study.
- All participants will have been diagnosed with multiple sclerosis according to the revised "MacDonald" criteria (Polman et al., 2011) at least 6 months beforehand.
- Participants will have an EDSS of 3.5 to 8.0 inclusive as measured through the WebEDSS with identified upper limb function problems
- Be able to attend the three focus group sessions in East London and must have the ability to understand and communicate in English.
- Have a documented assessment attempt for the cardboard 9-Hole Peg test (c9HPT) prior to focus group

3.2.2 EXCLUSION CRITERIA

- Participants will be ineligible to participate if any inclusion criteria are not met.
- Due to the nature of study we will be unable to recruit non English speaking participants. This is due to not having the resources to translate patient information or consent into different languages.

3.2.3 SAMPLE SIZE

There will be three focus group sessions and each will comprise of, between eight and ten participants (Krueger and Casey, 2009). Each participant will attend all three focus group. This number was decided upon recommendation from the literature (Kitzinger, 1994, 1995), previous research experience with focus groups (Thomson et al., 2015b), and the Barts MS Advisory Group, involving ten. As this is a qualitative study, the number of participants is small due to the role of their involvement in producing data.

3.2.4 SAMPLING TECHNIQUE

PwMS will be purposively sampled to ensure that a range of experiences of upper limb function, as described by their EDSS score, are captured and to ensure they are representative of the wider population of people living with MS. For example, people living with MS and have an

EDSS score of 4.0 will have very different upper limb experiences to those with an EDSS score of 8.0. The MS Consultant and MS Nurse will be aware of this sampling method and so will be selective in considering potential participants to speak to the researcher when recruiting in outpatients.

3.3 STUDY RECRUITMENT

The MS consultant and MS Nurse will identify potential patients of theirs who would be suitable to take part in the focus groups within their outpatient clinic over a duration of one month. If a patient meets the inclusion criteria and is happy to speak to the researcher, only then they will be approached. This will happen after their appointment while they are still in the outpatient department. The researcher will not approach patients without direction from the MS consultant or MS Nurse notifying them. This way we avoid approaching patients who would like to take part but are ineligible. Recruitment will approximately take one month and it is anticipated that three months later the focus groups will be completed with the study completed a further four months later.

3.4 INFORMED CONSENT

Patients will be given a verbal and written description of the study by the PI who has received GCP training and will answer any immediate questions or queries individuals may have.

The study patient information describes the purpose of the focus groups and describe that they will be asked to participate in discussions as well as contributing their experiences of living with MS. This information will also include details of how confidentiality will be maintained throughout the research process, how data will be recorded and their right to withdraw from the study or withdraw their consent at any point without having to supply a reason. Practical information such as details about the location of the facilities, car parking and transport arrangements will also be included. Study participants will either have travel expenses reimbursed or will have travel arranged for them by the PI. The patient information has been designed and reviewed in a previous PPI activity in June 2017 with the Barts MS Patient Advisory Group who stipulated that information about the study was to be presented in an engaging and easy to read format that communicates the patient-centred approach to the study.

Once the PI has spoken to patients, provided them with the printed study patient information and confirmed they would like to be involved, she will make a note of the patient's contact details (name, email, telephone number, address), the date the patient information is given to the patient and a convenient time to contact them within 24-48 hours to enable them to remember

the conversation, or at another convenient time agreed with them. Each participant will be telephoned or emailed as they prefer, to arrange dates, times and potentially transport for the three focus group sessions. Once verbal consent has been gained, written informed consent will be gained from each participant on attendance to the first focus group. To reduce patient burden and upper limb fatigue, written consent will be gained once per participant.

Each participant will be asked to initial and sign the consent form if they agree to their involvement in the study and sound recording of each session. The PI will later scan and post a copy of this consent form to the participants and store the original. A member of the patients care team, will the add the consent form to the patients notes. The PI will explain that all participants can withdraw, either before, or during the sessions, if they wish. The PI will also explain that there is no need to take part in any discussion they feel uncomfortable with.

3.4.1 WITHDRAWAL OF PARTICIPANTS

Participants may end their involvement at any time. We will advise them that we plan to keep all data collected from them before they end their involvement, unless they specify otherwise. However, if they require it, we will destroy all their data, which will be done securely. If data have been used in disseminations before withdrawal, we will advise participants that this information cannot be withdrawn.

Participants must tell us by the end of the study if they wish to avoid their data being included in reports, presentations and research materials. After this time, we can still remove data from our archives. If a participant withdraws from the study, they will not be replaced.

3.5 DATA COLLECTION PROCEDURES

If participants agree to take part in the research, they will be asked to complete a WebEDSS and c9HPT at home before the first focus group. When they arrive at the first focus group, they will be asked to share with the researcher, their WebEDSS and c9HPT score. This data will be used for descriptive purposes to describe the level of impairment that the focus group participants experience, which may contribute to the decisions that they make when developing the outcome measure.

Each of the focus groups will be sound recorded to capture the discussions around how patients contribute to the development of a PROM.

3.6 SCHEDULE OF ASSESSMENT

Task/ Weeks	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Focus group:																				
Recruitment in Outpatients																				
Arrange participant travel																				
Written Informed Consent																				
Complete WedEDSS																				
Complete c9HPT																				
Focus group 1																				
Focus group 2																				
Focus group 3																				
If opt-in, review draft publications, measures and protocol publication																				
Online survey:																				
Seek final QMUL ethical approval																				
Post survey online																				
Survey open																				
If opt-in, receive protocol publication																				

Chart 1: Chart showing time lines of MOT study involving both the three focus groups and online survey ethical application

3.7 STUDY PROCEDURES

3.7.1 FOCUS GROUP 1

The aim of the first focus group is to start the research process to identify upper limb activities important to people with MS. The PF will introduce the participants to the study topic, the focus

group process and to each other. The objective of the focus group is to engage the participants to develop questions for an online survey, to gather activities of upper limb function from another group of PwMS. The focus group will be approx. 3 hours long. The PF will lead the group through the three focus group sessions following the focus group topic guide (Appendix A). This topic guide was developed through meetings with the research team and Barts MS Advisory Group. Each of the focus groups will be sound recorded.

3.7.2 ONLINE SURVEY

By the end of the first focus group, the group will have developed questions that could be used to develop an online survey. This will be used to gather information on the different upper limb activities that are affected by living with MS with an EDSS of between 3.5 and 8.0. The survey will be created by the PI in survey monkey and posted on the Barts MS Research blog. Social media (specifically blogs) have been used to collect evidence of content validity and concept identification in new PROM development in the area of ALS (McCarrier et al., 2014; Rothman et al., 2015). The benefit of using social media, over face-to-face interaction is that the tool can be used to access a wide range of patients for the PROM development stage that would have not originally been accessed as it reaches people who can not travel, and is also a cost effective way of including more patients.

The survey aims to gather a minimum of 50 responses but we anticipate the survey gathering around 200 responses through the Barts MS Research Blog. The survey will be closed after two weeks giving time for the data to be prepared to be included in the second focus group. The response data will be anonymised of any identifiable information. If less than 50 responses are gathered, the survey will be left open for three weeks, but the second focus group will not be moved.

The respondents for the survey are not patients and so the survey is seeking local University ethical approval.

3.7.3 FOCUS GROUP 2

The aim of the second focus group is to review and discuss the results from the online survey. Working in groups of 5, each group has to work round tables reviewing the responses to identifying similarities, repetition and relevance. They will then identify all the environmental factors which contribute to the different ways to complete each activity.

3.7.4 FOCUS GROUP 3

The aim of the third focus group is to develop the format for the new PROM. The participants will discuss practical aspects such as the name of the tool, the format of administration (digital, paper or group based), how it should be distributed and discussing the need for instructions.

3.8 DATA ANALYSIS

Descriptive statistics will be used to analyse quantitative information to describe the sample explaining the range of EDSS and 9HPT scores of participants involved in both the focus groups and the online survey.

Qualitative data analysis will be used to determine how participants contributed to the PROM development and interacted as a group in this process. The process of Immersion/Crystallization described by Miller and Crabtree in 1992 will be used to analyse the data gathered from the focus group sessions. This method has been successfully used before by the researcher (Thomson et al., 2015b) and in similar research around analysing experiential knowledge (Dewar and Kennedy, 2016) and will enable the researcher to consider the unique role that patients experiential knowledge plays in PROM development. The Immersion/Crystallization method is unlike more formal schematic methods of data analysis and allows the researchers to become more engaged with the data to go beyond 'obvious interpretations to hear, see and feel the data,' (Borkan, 1999).

Data analysis will occur before (recording the initial engagement with the topic and any prior biases), during and after the data is collected to ensure it is high-quality (Miles and Huberman, 1994). This will allow the researcher to consider the influence of their own background on the final results and interpretation.

The research team will then meet and establish key themes as a framework for initial analysis from the teams previous knowledge and experience of PROM development activities and professional experience. Involving the research team in the analysis process can ensure pitfalls such as drawing premature conclusions or inability to reach closure, are avoided.

Discussion of the three focus groups will be transcribed verbatim by the researcher and subsequently coded along with the researcher's handwritten field notes recording group interactions and taking into consideration any 'crystallizations', insights or reflections noted during data collection in the field notes. This is key as a secondary aim of the study, is to analyse the interactions amongst the participants within the focus group sessions.

The PI will immerse themselves in the data to create sub-themes can then be associated to key themes. The PI will then aim to validate the established sub-themes by rereading the text, searching for alternative hypothesis and interpretations. The analysis will be presented back to the research team.

After the three stages of focus groups have finished, the PI will feedback the conclusions reported to the participants. This will give the participants an opportunity to express any further reflections or points for discussion. After the researcher has completed the analysis, a final account of the data will be created for dissemination.

3.9 END OF STUDY DEFINITION

The study will end four months after the third focus group has been completed. Within this time, the data will have been analysed, written up in a publication format and disseminated to both staff and patient groups. The study will last eight months in total.

3.10 POST STUDY ACTIVITIES

Once the study has finished, the newly developed PROM will be reviewed by the Barts MS Advisory Group to ensure it is easy to use (patients can complete it without assistance), brief (not too long in length), straightforward to answer (meaning of the rating system clear), to approve the content (familiar and easy to understand tasks) and ensure the scales are relevant. It will then be shared online for people to try. This activity is beyond the scope of this research study, but will continue.

4 STUDY TEAM AND ROLES

Role title	Role and activity in this research study
Principal Investigator and main researcher (PI): Alison Thomson	PPI lead for QMUL and organiser of Barts MS Advisory Group. Will administer and manage the study (protocol writing, research activity administration, travel organisation, payments, analysis, dissemination).
Patient Facilitator (PF): Harriet Smith	PwMS for 10 years; professional experience facilitating educational and service development projects within QMUL; contributed to developing focus group topic guide
Barts MS	Ten PwMS; contribute to departmental research projects over the

Advisory Group	past five years; contributed to developing the study design, focus group topic guide and visited the venue to evaluate it's appropriateness.
Qualitative Researcher (QR): Carol Rivas	Expert in patient experience, qualitative research and patient analysis who will be present in each focus group to both observe and contribute to data analysis.
Research Team	Team consisting of the Professor of Neurology (Gavin Giovannoni), Occupational Therapist (Karen Hoffman) (with experience of PROM development), QR (Carol Rivas) and PI (Alison Thomson).
Focus group of participants	PwMS adhering to study inclusion and exclusion criteria, recruited for this study to attend three focus groups in London.
Survey participants	PwMS; readers of the Barts MS Research Blog and involved in the survey over the blog.

Table 1: Description of roles and research activity

5 ETHICS

The PI will ensure that the study will be carried out in accordance with the ethical principles in the Research Governance Framework for Health and Social Care (Department of Health, 2005) and its subsequent amendments as applicable legal and regulatory requirements.

5.1 ETHICAL CONSIDERATIONS OF THE FOCUS GROUPS:

The PI and the QR have extensive experience conducting qualitative research projects involving patients and so are experienced at engaging and supporting patients through these projects. The PF also has experience facilitating patient focus groups with the PI who will be on hand at all times to provide reassurance, if necessary. The focus group topics have been developed with the Barts MS Advisory Group to ensure that they are appropriate for this group of participants.

Although the PF is a professional she is being involved in the study for both her professional facilitation skills and also her experience of living with MS. Therefore, there is a responsibly of the study team to ensure that she is fully supported and comfortable with her role. Care will be given to not overburden the PF and participants by expecting them to read large amounts of technical text, meet for extended periods of time or engage in energy draining tasks. Time schedules can be adjusted if needed. The PF will be verbally briefed about how to deal with any distressed participants and will carry details and contact numbers for suitable support. Both the

PI and PF are aware of Queen Mary Universities lone working policy which can be accessed here: http://hsd.qmul.ac.uk/A-Z/Lone%20Working/index.html. The PI will also keep a reflective diary throughout the research process to record her feelings throughout the process.

The PI will act in a respectful and professional manner when recruiting participants as it is important to spend time at the recruitment stage and at the start of each focus group ensuring the participants understand their role within the focus group and what is expected of them. The PI will strive to provide a supportive, safe environment to ensure individuals can talk freely and informally, allowing them to share on their own experiences which the researchers will have utmost respect for. The groups will have the opportunity to introduce themselves at the start of the sessions to help them feel at ease and to maintain privacy, a "Focus group in progress – Do not disturb," sign will be on the door. The focus group sessions will be held in a comfortable location, with soft furnishings, wheelchair access and accessible toilet facilities nearby and there will be a break in each session where refreshments will be provided.

Within the focus groups, discussion will be facilitated in a purposeful and open way, making sure everyone has the opportunity to take part. The well-being of the participants in the group will take precedence over the session itself. Participants talking about their experiences of living with MS may arouse feelings that need to be acknowledged and responded to sensitively. There is the potential that patients will share experiences of increasing disability and describe activities that they no longer can take part in or complete due to their disability and their MS. If any participant looks uncomfortable, the PF will call a short break and the session can be resumed if the participant(s) are happy to continue. If not, it may be necessary to end the session. The researchers can provide appropriate contact names and telephone numbers so that the patient participants can seek further support if they wish.

5.2 ETHICAL CONSIDERATIONS OF SURVEY

In the event that a participant from the online survey shares information through the service or directly with the PI that conveys information about the immediate safety or wellbeing of that participant, the PI will discuss this with the Research Team. If appropriate, the PI may respond with appropriate information. In this situation, the PI will act in compliance with GMC social media conduct guidelines (General Medical Council, 2013). The PI has extensive experience interacting with patients online via the Barts MS blog, has developed and delivered social media training for clinicians and has published articles on this topic (Thomson et al. 2017). This information, and the identity of any of the survey respondents will not be shared with the focus group participants.

6 PATIENT PUBLIC INVOLVEMENT

The involvement of PwMS in the design of this research study and development of this protocol has been key to ensure that the research process and activities are appropriate for PwMS to be included in as participants in focus groups with other PwMS. For example, considering factors such as the impact of fatigue for PwMS which has been carefully considered. Further, there is the possibility that the participants will share experiences of increasing disability and describe activities that they no longer can take part in or complete due to their disability and their MS. The study protocol has considered how to deal with this.

Following INVOLVE principles, services user have been involved in all stages of the research so far, including development of this protocol, reviewing the patient information, consent form and focus group topic guide. Further, this study has been designed based on learnings from the previous six years of delivering an active PPI programme of events within Barts MS at QMUL. The PI has extensive experience developing and delivering PPI initiatives.

The Barts MS Advisory Group (led by the PI and consisting of 10 PwMS who advise on all clinical and research projects from Barts MS) was involved in the study design and planning. They were instrumental in the development of the study protocol, activities, naming and study documentation. They were consulted at the inception of the study idea, throughout protocol development, have commented on and proof read the patient information and consent form, and will be again consulted at the end of the study with the study findings.

The focus group topic guide was developed by the PF and PI from the literature (Hobart, 2001; U.S. Department of Health and Human Services and Food and Drug Administration, 2009) and in consultation with the Barts MS Advisory Group and research team.

7 DATA HANDLING AND RECORD KEEPING

All research and personal data will be stored and managed in accordance with the Data Protection Act 1998 and the Research Governance Framework for Health and Social Care. Participants details (Names, addresses, email addresses and phone numbers) will not be shared. When they sign the consent form they will be given a "Participant Identification Number" which will be a randomly generated number, generated from a simple Excel random function. This randomised number will ensure anonymity of the patients throughout the research and analysis process.

We will give the participants the option to have their names or pseudonym included in the study publications.

The sound recorded data will remain on the recording device until back at the Blizard Institute building where it will be transferred to the storage device where it will be stored in a password protected folder on an encrypted hard drive. The sound recorders memory will be wiped.

The original sound recordings will then be stored by the PI, Alison Thomson, on a QMUL encrypted hard drive and stored in a locked cabinet in the Blizard Institute, a QMUL building. Only the PI will listen to the sound recordings. All documents related to the study will be archived at QMUL, including the listing of the identities of the participants involved in the study which will be kept separate from other documents. All documents relating to the study will be retained for at least 20 years after the end of the study before being destroyed in line with the then existing secure QMUL practice. Patient identifying data will be securely destroyed according to current QMUL practice at the end of the study.

8 DEVICES AND TOOLS

8.1 DEVICE: C9HPT

The cardboard 9HPT medical device will be used within this study to create a description of the participants MS that have taken part. The device is called the "Cardboard 9 Hole Peg Test" manufactured by "Barts-MS" and holds a CE mark. Participants for the focus group will be asked to complete the test at home before attending the first focus group. For participants of the online survey, they will be asked to supply their postal address and will be sent a c9HPT and asked to upload their results into the survey. The patient information will describe where they can view online instructions for how to self administer the test.

The c9HPT was developed by the Barts MS Research team and has been validated against the existing plastic version (Dubbisson et al., submitted). Its inclusion in this study is innovative as it will enable the research team to gather descriptive information from a large number of participants. They are made from cardboard and therefore are cost effective for the study to supply. Participants are welcome to keep the device after the study has completed. It can be viewed here: http://www.clinicspeak.com/9-hole-peg-test/

8.2 TOOL: WEBEDSS

The WebEDSS is an online questionnaire that both focus groups participants and survey participants will be asked to complete at home. It can be accessed from here: https://edss.clinicspeak.com/#/welcome

9 SAFETY REPORTING

There will be two researchers (PI and QR) and one PF in the focus group sessions that will take responsibility for the safety of the participants while taking part in the focus groups. This team will be aware of the building's safety procedures and emergency telephone number for the location. If any medical emergencies occur during a focus group session, a member of the team will contact 999 emergency services.

It is also likely that many of the focus group participants will be wheelchair users. The focus group venue has been informed of this and has both the bathroom and emergency facilities to host this number of wheelchair users as well as appropriate evacuation procedures in the event of an emergency.

If any safety measures occur then the PI will inform the sponsor and Research Ethics Committee via email of any events immediately.

MONITORING AND AUDITING

The Principal Investigator will retain the right to audit any study, study site or central facility. In addition, any part of the study may be inspected by the regulatory bodies and funders where applicable. Quality control checks of procedures and documents will be undertaken should a need be identified. The sponsor delegates this responsibility to the Principal Investigator. An internal audit may be conducted by the sponsor representative. For monitoring and audit purposes, the Sponsor and individuals from regulatory authorities may need to view data generated by the study.

10 FINANCE AND FUNDING

This study has been funded by the Horne Family Foundation. The research team applied to the foundation for funding in December 2016 for this specific study and other #ThinkHand initiatives.

The funding will cover the focus group venue hire, refreshments, resources and participants transport for the three focus group sessions. It will also cover the cost of a c9HPT for each focus group participants and survey responded (including postage and packaging). Following the INVOLVE guidelines, members of the PPI Barts MS Advisory Group are paid for their time and so is the patient facilitator.

11 INDEMNITY

Queen Mary University of London is the sponsor and has arranged suitable indemnity concerning negligent harm to be in place for this study.

12 DISSEMINATION OF RESEARCH FINDINGS

The results of the study will be reported first and foremost to the study participants along with a letter of thanks. They will be sent a one-page hand-outs summarizing the key findings from each focus group session and copies of any publications.

12.1 STUDY REPORT

The data will be analysed and produced in a Final Study report that can be accessed directly from the PI and will be sent around the study mailing list.

12.2 MAILING LIST

The research participants will have the option to be added to the study mailing list where they will be updated on the progress of the draft measure, development of the papers, and any poster or conference presentations. Once in use, biannual updates on use – how many people using, edits, etc. This newsletter will be co-authored by the PI and the PF. The aim of this method of dissemination is to continue the sense of involvement in the development of the tool.

12.3 ACADEMIC PEER-REVIEWED PUBLICATION

If participants would like, they can opt in if they would like their name included, their initials or a pseudonym in the academic publications. The participants will have an opportunity to review the publication before it is submitted to the journal. This will be posted to them on paper and via email. Unless the participants opt to have their name on the paper, their name will not be publically available.

12.4 PROTOCOL PAPER

The research team aim to publish this protocol, along with another research article describing the draft measure in one of the MS Journals. We believe that these journals have never published any research in this format before, but due to the topic of PROM development in MS, it will be of great interest. In this article, the funder, Horne Family Foundation will be acknowledged. They do not have any review or publication rights to the paper. The results will advance knowledge, improve the concrete situation and improve PROM design methodology. The researcher will publish articles in technical journals to reach colleagues; applied articles in periodicals read by practitioners and the public; and methodological and reflective articles in associational and professional journals designed to improve the practice of PPI research. The researcher will attend the European Committee for Treatment and Research in Multiple Sclerosis in September 2018 and RIMS conference in 2018 to present the data to contribute to the respective fields.

17 REFERENCES

Barrett, L., Cano, S., Zajicek, J., Hobart, J., 2013. Can the ABILHAND handle manual ability in MS? Mult. Scler. J. 19, 806–815.
Beresford, P., 2005. Developing the theoretical basis for service user/survivor-led research and equal involvement in research. Epidemiol. Psichiatr. Soc. 14, 4–9.
Bertoni, R., Lamers, I., Chen, C.C., Feys, P., Cattaneo, D., 2015. Unilateral and bilateral upper limb dysfunction at body functions, activity and participation levels in people with multiple sclerosis. Mult. Scler. J. 21, 1566–1574.
Borkan, J., 1999. Immersion/crystallization, in: Crabtree, B.F., Miller, W.L. (Eds.), Doing Qualitative Research. Sage Publications, Thousand Oaks, Calif, pp. 179–194.
Compston, A. (Ed.), 2005. McAlpine's multiple sclerosis, 4th ed. ed. Churchill Livingstone Elsevier, Philadelphia.
Compston, A., Coles, A., 2008. Multiple sclerosis. The Lancet 372, 1502–1517.
Cornwall, A., Jewkes, R., 1995. What is participatory research? Soc. Sci. Med. 1982 41, 1667–1676.
Department of Health, 2005. Research governance framework for health and social care: second edition. England.
Department of Health, 2001. The expert patient: a new approach to chronic disease management for the 21st century.
Dewar, B., Kennedy, C., 2016. Strategies for Enhancing "Person Knowledge" in an Older People Care Setting. West. J. Nurs. Res. 38, 1469–1488.
European Medicines Agency, 2005. Reflection paper on the regulatory guidance for the use of healthrelated quality of life (hrql) measures in the evaluation of medicinal products. London.
Fals-Borda, O., Rahman, M.A. (Eds.), 1991. Action and Knowledge: Breaking the monopoly with Participatory Action-Research. Practical Action Publishing, Rugby, Warwickshire, United Kingdom.

Fischer, J.S., Rudick, R.A., Cutter, G.R., Reingold, S.C., National MS Society Clinical Outcomes Assessment Task Force, 1999. The Multiple Sclerosis Functional Composite measure (MSFC): an integrated approach to MS clinical outcome assessment. Mult. Scler. 5, 244–250.
General Medical Council, 2013. Doctors' use of social media.
Hobart, J., 2001. The Multiple Sclerosis Impact Scale (MSIS-29): A new patient-based outcome measure. Brain 124, 962–973. doi:10.1093/brain/124.5.962
Jenkinson, C., Morley, D., 2016. Patient reported outcomes. Eur. J. Cardiovasc. Nurs. 15, 112–113.
Kitzinger, J., 1995. Qualitative research. Introducing focus groups. BMJ 311, 299–302.
Kitzinger, J., 1994. The methodology of Focus Groups: the importance of interaction between research participants. Sociol. Health Illn. 16, 103–121.
Kjeken, I., Ziegler, C., Skrolsvik, J., Bagge, J., Smedslund, G., Tovik, A., Dagfinrud, H.S., Petersson, I.F., Hagen, K.B., 2010. How to Develop Patient-Centered Research: Some Perspectives Based on Surveys Among People With Rheumatic Diseases in Scandinavia. Phys. Ther. 90, 450–460.
Krueger, R.A., Casey, M.A., 2009. Focus groups: a practical guide for applied research, 4th ed. ed. SAGE, Los Angeles.
Kurtzke, J.F., 1983. Rating neurologic impairment in multiple sclerosis: an expanded disability status scale (EDSS). Neurology 33, 1444–1452.
Lamers, I., Feys, P., 2014. Assessing upper limb function in multiple sclerosis. Mult. Scler. J. 20, 775–784.
Lamers, I., Maris, A., Severijns, D., Dielkens, W., Geurts, S., Van Wijmeersch, B., Feys, P., 2016. Upper Limb Rehabilitation in People With Multiple Sclerosis: A Systematic Review. Neurorehabil. Neural Repair 30, 773–793.
Leray, E., Yaouanq, J., Le Page, E., Coustans, M., Laplaud, D., Oger, J., Edan, G., 2010. Evidence for a two-stage disability progression in multiple sclerosis. Brain 133, 1900–1913.
McCarrier, K.P., Bull, S., Simacek, K.F., Wicks, P., Pierson, R.F., Wolfe, M., Cella, D., Rothman, M., 2014. Online social networks-based qualitative research to identify patient-relevant concepts in chronic lymphocytic leukemia. Value Health 17, A196.
Miles, M.B., Huberman, A.M., 1994. Qualitative data analysis: an expanded sourcebook, 2nd ed. ed. Sage Publications, Thousand Oaks.
Penta, M., Thonnard, J.L., Tesio, L., 1998. ABILHAND: a Rasch-built measure of manual ability. Arch. Phys. Med. Rehabil. 79, 1038–1042.
Polman, C.H., Reingold, S.C., Banwell, B., Clanet, M., Cohen, J.A., Filippi, M., Fujihara, K., Havrdova, E., Hutchinson, M., Kappos, L., Lublin, F.D., Montalban, X., O'Connor, P., Sandberg-Wollheim, M., Thompson, A.J., Waubant, E., Weinshenker, B., Wolinsky, J.S., 2011. Diagnostic criteria for multiple sclerosis: 2010 Revisions to the McDonald criteria. Ann. Neurol. 69, 292–302.
Pugliatti, M., Rosati, G., Carton, H., Riise, T., Drulovic, J., Vecsei, L., Milanov, I., 2006. The epidemiology of multiple sclerosis in Europe. Eur. J. Neurol. 13, 700–722.
Riazi, A., 2006. Patient-reported Outcome Measures in Multiple Sclerosis. Int. MS J. MS Forum 13, 92–99.
Rose, D., Evans, J., Sweeney, A., Wykes, T., 2011. A model for developing outcome measures from the perspectives of mental health service users. Int. Rev. Psychiatry 23, 41–46.
Rothman, M., Gnanaskathy, A., Wicks, P., Papadopoulos, E.J., 2015. Can We Use Social Media to Support Content Validity of Patient-Reported Outcome Instruments in Medical Product Development? Value Health 18, 1–4. doi:10.1016/j.jval.2014.10.001

Savory, C., 2010. Patient and public involvement in translative healthcare research. Clin. Gov. Int. J. 15, 191–199.
Schwid, S.R., Goodman, A.D., Mattson, D.H., Mihai, C., Donohoe, K.M., Petrie, M.D., Scheid, E.A., Dudman, J.T., McDermott, M.P., 1997. The measurement of ambulatory impairment in multiple sclerosis. Neurology 49, 1419–1424.
Smith, S., Weldring, T., 2013. Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). Health Serv. Insights 61.
Thomson, A., Davis, A., Paterson, A., Giovannoni, G., Schmierer, K., 2015a. Designing an information resource to explain diagnostic lumbar puncture and promote best practice. Presented at the Association of British Neurologists Annual Meeting, Harrogate.
Thomson, A., Espasandin, M., Denholm, T., Giovannoni, G., 2011. Analysing and redesigning the outpatient experience for people with multiple sclerosis, in: 5th Joint Triennial Congress of the European and Americas Committees for Treatment and Research in Multiple Sclerosis. Presented at the European and Americas Committees for Treatment and Research in Multiple Sclerosis, Amsterdam, The Netherlands.
Thomson, A., Rivas, C., Giovannoni, G., 2015b. Multiple sclerosis outpatient future groups: improving the quality of participant interaction and ideation tools within service improvement activities. BMC Health Serv. Res. 15.
Trujols, J., Portella, M.J., Iraurgi, I., Campins, M.J., Siñol, N., Cobos, J.P. de L., 2013. Patient-reported outcome measures: Are they patient-generated, patient-centred or patient-valued? J Ment Health 22, 555–562.
U.S. Department of Health and Human Services, Food and Drug Administration, 2009. Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims.
Wicks, P., 2015. Commentary: Measuring what matters: the case for patient generated PROMS. BMJ 350, h54–h54.
Yozbatiran, N., Baskurt, F., Baskurt, Z., Ozakbas, S., Idiman, E., 2006. Motor assessment of upper extremity function and its relation with fatigue, cognitive function and quality of life in multiple sclerosis patients. J. Neurol. Sci. 246, 117–122.

18 APPENDICES

A Focus Group Topic Guide

Focus Group 1

1. **Welcome and introduction**
   The facilitator will start by introducing themselves and the other researchers in the room. She will give a brief overview of the research study and check that all participants are happy to continue, and to be audio recorded. It will be made clear that if there are any questions, to either ask at any time, or mention to a researcher.

   Run through the timings of the focus group, mentioning breaks and refreshments.

   Safety information will be shared about the facilities and also ensuring confidentiality of any information that is shared within the focus group.

   As an ice-breaking activity, participants are to turn to person next to them and share an interesting fact. Then we share this with group.

2. **Background to the study**
   - **a.** Introduction to the study topic area of PROMS and their role in upper limb function for people with MS.
   - **b.** Introduce the aim of this research
     - **i.** Run three focus groups to find out:
       1. What are the relevant UL activities for PwMS?
       2. How do you complete these at home?
       3. If we created a PPROM, what would this be?
   - **c.** Process for developing PROM (FDA)
     - **i.** Focus group 1 – Design online survey
     - **ii.** Run survey
     - **iii.** Focus group 2 – Discuss survey results
     - **iv.** Focus group 3 – Develop format for new PROM

3. **Group Discussion**
   The facilitator will hold an open discussion with the participants around how their upper limb function, and the ability to complete everyday tasks has been affected by their MS.

   This will then lead onto a discussion about their experience of completing PROMS and the role and meaning of measurement in their lives. Is this something that they find important or useful?

4. **Break**

5. **Design an online survey to collect a range of UL activities:**
   This section will
   - **a.** Design survey questions
   - **b.** How should we collect the survey responses? E.g. text, written, video, image (non-identifiable)
   - **c.** How will we discuss this information?
   - **d.** Appropriate information for survey respondents - within the survey: consent, results.

6. **Close and next steps**
   Thank them for taking part in the focus group and describe what the next steps are.

Focus group 2

1. **Welcome:**
   Outline session timing reiterating important information about logistics and confidentiality.

2. **Discuss survey results**
   Discuss the general response from survey including numbers of responses and any comments left relating to format of survey

   All of the participants will be given printed copies of the survey results and be asked to read through them all.

   - What are the common themes or categories of activities that come up?
   - Are there similar locations, formats or purpose of activities?

3. **Break**

4. **Create terms of measurement**
   What is a meaningful way to measure these activities? Is it success if completing it or doing it quickly? Are headings "impossible, difficult, easy" meaningful or useful?

5. **Close and next steps**

Focus Group 3:

1. **Welcome:**
   Outline session timing reiterating important information about logistics and confidentiality.

   - **a.** Re-write new instruction
   - **b.** How and where does this PROM exist
   - **c.** What does it do, and enable people to do?

2. **Designing the PROM:**
   - **a.** Decide method of administration: self-administration, interview, group activity
   - **b.** Format of administration: paper based/ digital
   - **c.** Group to decide naming of the tool
   - **d.** Develop instructions of use.
   - **e.** What to do with results

3. **Break**

4. **Close and next steps for dissemination**

   Thank them for taking part in the study and describe what the next steps are. Discuss logistics of compensation for travel expenses.

Appendix D: NRES MOT study approval

NHS
Health Research Authority

Miss Alison Thomson
Lecturer in Public Engagement and Patient Public Involvement
Queen Mary, University of London
Centre for Neuroscience & Trauma Blizard
4 Newark Street, Blizard Institute, QMUL
London
E1 2AT

Email: hra.approval@nhs.net

07 November 2017

Dear Miss Thomson

Letter of HRA Approval

Study title:	**Measurement on Our Terms: exploring the role of patients when developing an upper limb Patient Reported Outcome Measurement for Multiple Sclerosis**
IRAS project ID:	**228062**
Protocol number:	**0.5**
REC reference:	**17/LO/1684**
Sponsor	**Queen Mary, University of London**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators",* issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **228062**. Please quote this on all correspondence.

Yours sincerely

Maeve Ip Groot Bluemink
Assessor

Email: hra.approval@nhs.net

Copy to: *Dr Sally Burtles, Queen Mary, University of London – Sponsor Contact*
Pushpen Joshi, Queen Mary, University of London – Lead R&D Contact

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Covering letter on headed paper [Cover Letter]		13 September 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		24 July 2017
Interview schedules or topic guides for participants [Topic Guide]	0.1	15 August 2017
IRAS Application Form [IRAS_Form_14092017]		14 September 2017
Letter from funder [Funding Letter from Horne Family Charitable Foundation]		22 December 2016
Letter from sponsor [Provisional Sponsorship letter from QMUL]		12 September 2017
Participant consent form [Patient Consent Form]	0.4	19 October 2017
Participant information sheet (PIS) [Patient information]	0.5	19 October 2017
Referee's report or other scientific critique report [Peer Review confirmation]		18 August 2017
Research protocol or project proposal [MOT Research Protocol]	0.5	12 September 2017
Summary CV for Chief Investigator (CI) [CI Alison Thomson CV]		15 August 2017
Summary CV for supervisor (student research) [Supervisor 1 CV]		25 July 2017
Summary CV for supervisor (student research) [Supervisor 2 CV]		01 June 2017

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations*, *capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Dr Sally Burtles
Tel: 020 7882 7265
Email: sponsorsrep@bartshealth.nhs.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards?	Comments
1.1	IRAS application completed correctly	Yes	The applicant confirmed that NHS activity is limited to patient identification and initial approach.
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	This is a non-commercial single site study taking place in the NHS where that single NHS organisation's partner University is the study sponsor. Therefore no study agreements are expected.
4.2	Insurance/indemnity arrangements assessed	Yes	Sponsor's insurance policy will cover the design, management and conduct of the study.

Section	HRA Assessment Criteria	Compliant with Standards?	Comments
			Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	External funding has been secured from the Horne Family Foundation.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	Clarification has been requested around access to medical records.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Favourable Opinion was issued by the London – Stanmore REC
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

The applicant confirmed that only The Royal London Hospital (Barts Health NHS Trust) will be used for patient identification and initial approach but no consent or research activities will be conducted at the NHS site.

This is a non-commercial single site study taking place in the NHS where that single NHS organisation's partner University is the study sponsor. There is only one site type involved in the research.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If Chief Investigators, sponsors or Principal Investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the Chief Investigator, sponsor or Principal Investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

This is a non-commercial single site study taking place in the NHS where that single NHS organisation's partner University is the study sponsor. The participating NHS organisation will therefore **be expected to formally confirm their capacity and capability to host this research according to local requirements.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.

The Assessing, Arranging, and Confirming document on the HRA website provides further information for sponsors and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor's position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Principal Investigator (PI) is expected for this type of study.

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken.

The activities at the participating NHS organisation will be undertaken by local staff therefore it is expected that adequate contractual relationship with the host organisation are already in place.

Where contractual arrangements are not already in place, external staff (or similar) undertaking research activities would be expected to obtain Honorary Research Contracts on the basis of a Research Passport (if university employed) or a Letter of Access on the basis of an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed).

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England in study set-up.

- The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.
- Some participants may also be recruited outside the NHS and some activity may take place outside the NHS. HRA approval does not cover activity outside the NHS. Before recruiting or undertaking activity outside the NHS the research team must follow the procedures and governance arrangements of responsible organisations.

Appendix E: QMUL MOT study approval

Queen Mary, University of London
Room W117
Queen's Building
Queen Mary University of London
Mile End Road
London E1 4NS

Queen Mary Ethics of Research Committee
Hazel Covill
Research Ethics Administrator
Tel: +44 (0) 20 7882 7915
Email: h.covill@qmul.ac.uk

c/o Dr Alison Thomson
Centre for Neuroscience and Trauma
Blizard Institute
Queen Mary University of London
Mile End Road
London

18th October 2017

To Whom It May Concern:

Re: QMERC2017/52 – Measurement on our Terms: Survey (MOT: Survey)

The above study was deferred for later review by The Queen Mary Ethics of Research Committee (Panel A) on the 6th September 2017; full approval was ratified by Panel's Email Action on the 10th October 2017.

This approval is valid for a period of two years, (if the study is not started before this date then the applicant will have to reapply to the Committee).

Yours faithfully

Dr Helen Jenner – QMERC Chair.

Appendix F: QMUL sponsorship

Non-CTIMPs Provisional Sponsorship

Joint Research Management Office
Queen Mary Innovation Centre
5 Walden Street
London
E1 2EF

Tel: 020 7882 7260
Fax: 020 7882 7276
Email: Sponsorsrep@bartshealth.nhs.uk

12th September 2017

Alison Thomson
Lecturer in Public Engagement and Patient
Public Involvement
Centre for Neuroscience and Trauma
The Blizard Institute
Barts and The London School of Medicine and Dentistry
64 Turner Street
London
E1 2AB

Dear Miss Thomson,

Declaration of QMUL Provisional Sponsorship

PROJECT TITLE:	**Measurement on Our Terms: exploring the role of patients when developing an upper limb Patient Reported Outcome Measurement for Multiple Sclerosis**
Protocol version #:	**0.5**
Protocol date:	**12th September 2017**
ReDA Reference:	**12062**
Host site:	**QMUL**

The above referenced study and supporting documentation have been reviewed and Sponsorship, as defined in the Research Governance Framework for Health and Social Care 2005 and/or the Medicines for Human Use (Clinical Trials) Regulations 2004, will be provided on the condition that the relevant regulatory body approvals are obtained and the "Conditions of Sponsorship" are adhered to.

A further declaration of formal Sponsorship will be made by the Joint Research Office on proof of relevant regulatory body approval/s being in place.

Please contact the Joint Research Office if you require any further guidance or information on any matter mentioned above.

Yours sincerely

Sally Burtles
Director of Research Services & Business Development

Cc: Alison Thomson

Appendix G: IRAS form

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Measurement on Our Terms (MOT)

1. Is your project research?

(•) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
(•) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation? ( ) Yes (•) No
b) Will you be taking new human tissue samples (or other human biological samples)? ( ) Yes (•) No
c) Will you be using existing human tissue samples (or other human biological samples)? ( ) Yes (•) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

[x] England
[ ] Scotland

[ ] Wales
[ ] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

(•) England
( ) Scotland
( ) Wales
( ) Northern Ireland
( ) This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

[x] IRAS Form
[ ] Confidentiality Advisory Group (CAG)
[ ] National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

( ) Yes (•) No

5. Will any research sites in this study be NHS organisations?

(•) Yes ( ) No

5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS Support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or a Diagnostic Evidence Co-operative in all study sites?

Please see information button for further details.

( ) Yes (•) No

Please see information button for further details.

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?

Please see information button for further details.

( ) Yes (•) No

The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form (PAF) immediately after completing this project filter question and before submitting other applications. Failing to complete the PAF ahead of other applications e.g. HRA Approval, may mean that you will be unable to access NIHR CRN Support for your study.

6. Do you plan to include any participants who are children?

( ) Yes (•) No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

( ) Yes (•) No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

( ) Yes (•) No

9. Is the study or any part of it being undertaken as an educational project?

(•) Yes ( ) No

Please describe briefly the involvement of the student(s):
This study is being led by Alison Thomson as part of her professional role as Lecturer in Patient Public Involvement and Public Engagement in Science at Queen Mary University of London (QMUL). The outcome measure being developed through this study is a requirement Alison's professional role.

Alison is also completing a PhD registered at Goldsmiths, University of London looking at how to improve the patient experience for people with MS. Part of this study, specifically the exploration of patient experiential knowledge in this PROM development process (i.e. how patients can discuss improvements for other patients based on their own experiences), will be written about in the thesis. This discussion will only form a small part of the thesis.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

(•) Yes ( ) No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

( ) Yes (•) No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

( ) Yes (•) No

Integrated Research Application System
Application Form for Research involving qualitative methods only

IRAS Form (project information)

Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Measurement on Our Terms (MOT)

Please complete these details after you have booked the REC application for review.

REC Name:
London Stanmore

REC Reference Number: 17/LO/1684

Submission date: 14/09/2017

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Measurement on Our Terms: exploring the role of patients when developing an upper limb Patient Reported Outcome Measurement for Multiple Sclerosis

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Miss	Alison/A	Thomson
Address	Centre for Neuroscience & Trauma Blizard		
	Blizard Institute, QMUL		
	4 Newark Street, Whitechapel		
Post Code	E1 2AT		
E-mail	a.thomson@qmul.ac.uk		
Telephone	02078822367		
Fax			

Give details of the educational course or degree for which this research is being undertaken:
Name and level of course/ degree:

PhD in Design

Name of educational establishment:
Goldsmiths, University of London

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Alex	Wilkie
Address	Department of Design		
	Goldsmiths		
	University of London, New Cross, London		
Post Code	SE14 6NW		
E-mail	a.wilkie@gold.ac.uk		
Telephone			
Fax			

Academic supervisor 2

	Title	Forename/Initials	Surname
	Professor	Bill	Gaver
Address	Department of Design		
	Goldsmiths		
	University of London, New Cross, London		
Post Code	SE14 6NW		
E-mail	w.gaver@gold.ac.uk		
Telephone			
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Miss Alison/A Thomson	☑ Dr Alex Wilkie ☑ Professor Bill Gaver

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- ◉ Student
- ○ Academic supervisor
- ○ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Alison	Thomson
Post	Lecturer in Public Engagement and Patient Public Involvement		
Qualifications	BSc Hons, MA RCA		
ORCID ID			
Employer	Queen Mary, University of London		
Work Address	Centre for Neuroscience & Trauma Blizard		
	4 Newark Street, Blizard Institute, QMUL		
	London		
Post Code	E1 2AT		
Work E-mail	a.thomson@qmul.ac.uk		
* Personal E-mail	a.thomson@qmul.ac.uk		
Work Telephone	02078822367		
* Personal Telephone/Mobile	07846598417		
Fax			

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Dr	Sally	Burtles
Address	Joint Research Management Office (JRMO)		
	Queen Mary Innovation Centre, Lower Ground Floor		
	5 Walden Street , London		
Post Code	E1 2EF		
E-mail	sponsorsrep@bartshealth.nhs.uk		
Telephone	020 7882 7265		
Fax	020 7882 7276		

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	
Sponsor's/protocol number:	0.5
Protocol Version:	0.5
Protocol Date:	12/09/2017
Funder's reference number:	
Project website:	

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)"

section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

Patient Reported Outcome Measures (PROMs) are tools used in clinical practice to assess health, illness and benefits of health care from the patient's perspective. However, the PROMs currently used to measure the impact of Multiple Sclerosis (MS) on a persons upper limb function have been developed with little patient involvement resulting in tools which are not condition specific nor up to date. In other health fields, such as mental health for example, patients have been involved in the entire PROM development process therefore creating more effective measurement tools.

This research seeks to explore how people living with MS can contribute their experiences of living with the chronic condition to the development of a new upper limb PROM.

Participants will be asked to attend three focus groups lasting an average of three hours over a three month period and contribute their experience of how their MS has affected their ability to complete upper limb activities and tasks. They will also be able to discuss their experience of completing PROMs and the role of measurement in their clinical care. Explorative methods, such as focus groups, have been previously used to involve patients in service development and improvement projects, but not in PROM development with people with MS.

The study is funded by the Horne Family Foundation and participants will be recruited from the Barts MS Service at the Barts Health NHS Trust outpatient department.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

It is not the researchers' intent to cause undue worry or concern to any of the participants involved in this research when discussing their health and experiences. Therefore in the design and planning of the study, the involvement of people with MS within the Barts MS Patient Advisory Group was key to ensure that the research process and discussion topics are appropriate for use by other people with MS. For example, considering factors such as the impact of fatigue when attending the focus groups for people with MS has been carefully considered in the topic guide and in the discussions themselves. Further, there is the possibility that the participants will share experiences of increasing disability and describe activities that they no longer can take part in or complete due to their disability and their MS.

The study has addressed these issues by including activities to make participants feel supported to share their experiences, including professional facilitation skills within the discussions and ensuring the relevant professional roles can be accessed if necessary.

The focus groups will be facilitated by a professional facilitator (PF) who is also living with MS. Although the PF is a professional she is being involved in the study for both her professional facilitation skills and also her experience of living with MS. Therefore, there is a responsibly of the study team to ensure that she is fully supported and comfortable with her role. Care will be given to not overburden the PF and participants by expecting them to read large amounts of technical text, meet for extended periods of time or engage in energy draining tasks. The PF will be verbally briefed about how to deal with any distressed participants and will carry details and contact numbers for suitable support.

Before starting each focus group session, in the opening address, the PF will reiterate the purpose of the focus group, based on the written information previously provided. The groups will have the opportunity to introduce themselves at the start of the sessions to help them feel at ease and that there will be regular breaks where refreshments will be provided. The PF will be aware and sensitive of any potential upsetting or concerning topics that are discussed. Although the PF has worked on service development projects with the research team before, it is the PIs responsibility to ensure facilitating these discussions and listening to others experiences does not over wheim or upset her.

During the focus group sessions a second researcher, who is experienced in qualitative research will be in the room alongside the PI. This is to ensure the PI and PF are supported from the perspective of safety (lone worker) and to ensure a coherent interpretation of the research themes identified during the focus groups. Both are aware of Queen Mary Universities lone working policy which can be accessed here: http://hsd.qmul.ac.uk/A-Z/Lone%20Working/index.html. Each session will be followed by a verbal de-brief discussion between the PI, the qualitative researcher (QR) and the PF to ensure that all questions have been answered and the PF feels supported.

The wider research team, consisting of the Professor of Neurology and an occupational therapist, will meet throughout the study to support the PI and the analysis process. This will ensure an unbiased perspective is maintained throughout the study.

The PI will be writing up part of this study for a PhD qualification and will be supported by two supervisors when doing this once analysis is completed. The supervisors will not have access to any original data.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- [ ] Case series/ case note review
- [ ] Case control
- [ ] Cohort observation
- [ ] Controlled trial without randomisation
- [ ] Cross-sectional study
- [ ] Database analysis
- [ ] Epidemiology
- [ ] Feasibility/ pilot study
- [ ] Laboratory study
- [ ] Metanalysis
- [x] Qualitative research
- [ ] Questionnaire, interview or observation study
- [ ] Randomised controlled trial
- [x] Other (please specify)

Focus groups and descriptive statistics

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

The principle research objective is to identify how patients with MS can contribute to PROM development.

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to*

a lay person.

The secondary research objective is to develop a PROM to evaluate upper limb function in people with MS.

A further research objective is to explore how patients experiential knowledge can contribute to the development of a PROM.

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

The research will engage people with MS throughout the whole process of patient reported outcome measures (PROM) development. There has been similar research which looked at developing outcome measures with patients in mental health, but not specifically looking at upper limb function in MS. Within the field of MS, new PROMS to measure upper limb function are being developed, but they are not interested in exploring the potential for patients to be involved in this process, contributing their experiences of living with the chronic illness.

The research will discover how people with MS experience effects of MS on their day to day activities, how they feel when they complete PROMs and take part in measurement activities. Discussions will explore and determine how patients would like to receive PROMs from the health service and the role that measurement plays in their monitoring of their own disease. This will give insights on how to improve PROM design and could lead to improved measurement data. This qualitative study includes people with different experiences of living with MS from different perspectives which will increase the chance of generating innovative ideas that have a good chance of working in practice.The research will contribute to the literature on patient generated PROMs, exploring how the focus group participants make sense of other patients experiences.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This is a mixed method study consisting of three qualitative focus groups and an online survey. Within the study, there is a nested analysis of the impact of experiential knowledge on the development of a PROM. This study uses a focus group method to involve patient participants in the PROM development process. The focus group sessions will enable interactions between participants to help with the generation of new ideas and personal reflections based on their experiences of living with MS. The three focus groups will take place over three months with an on-line survey posted after the first focus group to identify topics for the subsequent focus groups. Participants will then discuss the results of the survey and develop categories for a new PROM to measure upper limb function for PwMS.

PwMS will be purposively sampled to ensure that a range of experiences of upper limb function, as described by their expanded disability status score (EDSS) score, are captured and to ensure they are representative of the wider population of people living with MS. For example, people living with MS and have an EDSS score of 4.0 will have very different upper limb experiences to those with an EDSS score of 8.0. The MS Consultant and MS Nurse will be aware of this sampling method and so will be selective in considering potential participants to speak to the researcher when recruiting in The Royal London Hospital outpatient department.

Once the PI has spoken to patients, provided them with the printed study patient information and confirmed they would like to be involved, she will make a note of the patient's contact details (name, email, telephone number, address), the date the patient information is given to the patient and a convenient time to contact them within 24-48 hours to enable them to remember the conversation, or at another convenient time agreed with them. Each participant will be telephoned or emailed as they prefer, to arrange dates, times and potentially transport for the three focus group sessions. Once verbal consent has been gained, written informed consent will be gained from each participant on attendance to the first focus group. To reduce patient burden and upper limb fatigue, written consent will be gained once per participant.

Once participants has agreed to take part in the study they will be asked to complete a Web-based Expanded Disability Status Scale survey (WebEDSS) and cardboard 9 Hole Peg Test (c9HPT). These will both be used to describe the type of MS that each of the focus group participants have. The WebEDSS can be completed at home, on their own computer, in their own time, taking approximately 10 minutes. The c9HPT will be posted to the participants home and again, completed in their own time. Participants will be asked to share the results of both tests with the PI either when they are communicating on email or the phone to organise the date of the focus group, or on arrival of the first focus group. This also takes 10 minutes to complete.

Focus group overview:
Focus groups of between eight and ten people will be used to collect qualitative data via sound recordings that will

provide detailed insights into individuals understanding and experiences of living with MS, how this affects their upper limb function and also how this can be measured. Participants will work as a group to design a survey for other patients, analyse these results then develop a new PROM.

Detailed description of focus group sessions:
The aim of the first focus group is to start the research process to identify upper limb activities important to people with MS. The PF will introduce the participants to the study topic, the focus group process and to each other. The objective of the focus group is to engage the participants to develop questions for an online survey, to gather activities of upper limb function from another group of PwMS. The focus group will be approx. 3 hours long. The PF will lead the group through the three focus group sessions following the focus group topic guide. This topic guide was developed through meetings with the research team and Barts MS Patient Advisory Group.

By the end of the first focus group, the group will have developed questions that could be used to develop an online survey. This will be used to gather information on the different upper limb activities that are affected by living with MS with an EDSS of between 3.5 and 8.0. The survey will be created by the PI and posted on the Barts MS Research blog. Social media (specifically blogs) have been used to collect evidence of content validity and concept identification in new PROM development in the area of ALS. The benefit of using social media, over face-to-face interaction is that the tool can be used to access a wide range of patients for the PROM development stage that would have not originally been accessed as it reaches people who can not travel, and is also a cost effective way of including more patients.

The survey aims to gather a minimum of 50 responses but we anticipate the survey gathering around 200 responses through the Barts MS Research Blog. The survey will be closed after two weeks giving time for the data to be prepared to be included in the second focus group. The response data will be anonymised of any identifiable information. If less than 50 responses are gathered, the survey will be left open for three weeks, but the second focus group will not be moved.

The aim of the second focus group is to review and discuss the results from the online survey. Working in groups of 5, each group has to work round tables reviewing the responses to identifying similarities, repetition and relevance. They will then identify all the environmental factors which contribute to the different ways to complete each activity.

The aim of the third focus group is to develop the format for the new PROM. The participants will discuss practical aspects such as the name of the tool, the format of administration (digital, paper or group based), how it should be distributed and discussing the need for instructions.

The focus groups will be held in a community cafe meeting room in the Queen Elizabeth Olympic Park, East London, lasting an average of three hours, led by the PF in conjunction with the PI. They will be held between two and three weeks apart to ensure some memory of the previous discussion and to allow the study to keep up some momentum. This space has been chosen by as it is not only has the capacity to hold a meeting with a number of wheelchair users with a taxi drop off space at the entrance but it will provide a safe and respectful environment which is important for focus groups to be held in a non-medical venue in the belief that this will encourage participants to speak more freely. The Camden Society have provided a letter to confirm they are happy for the Unity Café to be used as a research site.

The study will end four months after the third focus group has been completed. Within this time, the data will have been analysed, written up in a publication format and disseminated to both staff and patient groups. The study will last eight months in total.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [x] Management of the research
- [ ] Undertaking the research
- [x] Analysis of results
- [ ] Dissemination of findings
- [ ] None of the above

Give details of involvement, or if none please justify the absence of involvement.
The Barts MS Patient Advisory Group were consulted and their comments and suggested amendments were incorporated and are reflected in the design of the research methodology, the focus group topic guide, patient information and consent forms. They visited the space to evaluate it's appropriateness for this research study and agree that it will support the study's aims of providing a supportive, relaxed atmosphere that is appropriate for the study.

Focus group participants will be informed of the findings of the research when it has concluded. The participants will receive via the postal system a written description of the conclusions of the focus group if they are interested, along with any written publications.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- [ ] Blood
- [ ] Cancer
- [ ] Cardiovascular
- [ ] Congenital Disorders
- [ ] Dementias and Neurodegenerative Diseases
- [ ] Diabetes
- [ ] Ear
- [ ] Eye
- [ ] Generic Health Relevance
- [ ] Infection
- [ ] Inflammatory and Immune System
- [ ] Injuries and Accidents
- [ ] Mental Health
- [ ] Metabolic and Endocrine
- [ ] Musculoskeletal
- [x] Neurological
- [ ] Oral and Gastrointestinal
- [ ] Paediatrics
- [ ] Renal and Urogenital
- [ ] Reproductive Health and Childbirth
- [ ] Respiratory
- [ ] Skin
- [ ] Stroke

Gender:	Male and female participants
Lower age limit: 18	Years
Upper age limit:	No upper age limit

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Participants will be invited to take part in the focus group sessions if they meet the inclusion criteria of being able to give informed consent without assistance.

Participants must be over the age of 18 and have been diagnosed with Multiple Sclerosis more than 6 months ago and have an EDSS of between 3.5 and 8.0.

Participants must be able to attend all three focus group sessions in East London.

Participants must have documented assessment attempts for Expanded Disability Status Scale (EDSS), via the WebEDSS and cardboard 9-Hole Peg test (c9HPT) prior to the focus groups.

Participants must also be able to understand and be able to communicate in English.

Participants who will be invited to complete the online survey that is generated from the first focus group will be readers of the Barts MS Research Blog. This group of participants will not be recruited as patients so are subject of local ethical approval only which is being requested.

They will also be asked to complete the WebEDSS and c9HPT before completing the survey and must be over the age of 18 and have been diagnosed with Multiple Sclerosis more than 6 months ago with an EDSS of between 3.5 and 8.0.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Participants will be ineligible to participate if any inclusion criteria are not met. For example, if they do not want to complete the c9HPT or WebEDSS score.

Due to the nature of study we will be unable to recruit non English speaking participants. This is due to not having the resources to translate patient information or consent into different languages.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Recruitment	1		10 mins	The Principal Investigator will speak to patients in the outpatient department at Barts Health NHS Trust and provide them with the printed study patient information. If they confirm they would like to be involved, she will make a note of the patient's contact details (name, email, telephone number, address), the date the patient information is given to the patient and a convenient time to contact them within 24-48 hours to enable them to remember the conversation, or at another convenient time agreed with them.
Phone call or email to patients to arrange focus group times and dates	1		15 minutes	Each participant will be telephoned or emailed as they prefer, to arrange dates, times and potentially transport for the three focus group sessions.
Written informed consent	1		10 mins	The Principal Investigator will ask each participant to initial and sign the consent form at the start of the first focus group in the community cafe in the Queen Olympic Park if they agree to their involvement in the study and sound recording of each session.
WebEDSS	1		10 minutes	Patient will conduct on their own at home
Cardboard 9 Hole Peg Test	1		10 minutes	Patient will conduct on their own at home
Focus group 1	1		3 hours	Principal Investigator, patient facilitator and the qualitative researcher. Location to be a community cafe in the Queen Elizabeth Olympic Park.
Focus Group 2	1		3 hours	Principal Investigator, patient facilitator and the qualitative researcher.. Location to be a community cafe in the Queen Elizabeth Olympic Park.
Focus Group 3	1		3 hours	Principle Investigator, patient facilitator and the qualitative researcher. Location to be a community cafe in the Queen Elizabeth Olympic Park.
Dissemination of results	1		5 minutes	Principal Investigator - results to be emailed or posted to patients home address

A21. How long do you expect each participant to be in the study in total?

We expect participants to be in the study for three months.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Talking about previous health care experiences may arouse feelings that need to be acknowledged and responded to sensitively. The wellbeing of the participants in the group will take precedence over the session itself. During the focus group, if necessary, the participants will be offered and encouraged to take short breaks throughout the session. Sessions will only resume if all participants are in agreement and comfortable with the session resuming. If not, the session may be terminated early and this will be recorded in the focus group session notes. The researchers will provide appropriate contact names and telephone numbers for all participants to seek further support if they wish. If there are any sensitive or disturbing issues discussed at the meetings for which the researchers are unable to manage themselves then support services have been approached as follows. The Patient Advisory Liaison service (PALS) have agreed to be contacted by individual patients in this instance, and so has another consultant Neurologist who is not involved in the study, but who knows about it. Both of these contact details are in the patient information.

The PF and the PI will facilitate the discussions in a purposeful and open way, making sure everyone has the opportunity to take part. The researcher will reiterate that participants can contact either the PI or Professor of Neurology, part of the research team, if they have any issue they would like to discuss about the research activity.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

(•) Yes ( ) No

If Yes, please give details of procedures in place to deal with these issues:

The researcher and facilitator will encourage discussion, through a series of question prompts to the group, written in the focus group topic guide, to encourage individuals to share their experiences and facilitate discussions in the sessions.

There is a possibility that the discussions may include topics of diagnosis, symptoms and experiences of increased disability from patients. The researchers and PF will listen to the participants stories and provide sensitive responses to any statements. The researchers will also be mindful that there are other patients involved in the group and ensure that these stories do not cause upset or alarm. If this situation does arise, the researchers will remind the group that the purpose of the research activity is to discuss feelings relating to completing activities. If necessary, the researcher can suggest a refreshment break and move onto another topic after the break.

If information is disclosed that requires followup action or notification, the researcher will immediately discuss this with the more experienced researcher and then inform the Professor of Neurology. All topics of conversation and interactions will be written up by the PI.

A24. What is the potential for benefit to research participants?

There are no immediate benefits for participants in taking part in this research. It is anticipated that in the future the newly developed PROM will be used by patients and benefit anyone who uses it.

A26. What are the potential risks for the researchers themselves? *(if any)*

Potential risks to the researchers and the PF have been discussed with the research team and the PIs supervisors. If there are any situations within the research activity where the PF or the PI feels uncomfortable by either approaching participants or in the support of the PF of the focus groups, the PI will inform the Professor of Neurology and her supervisors immediately. Both the PI and PF are aware of Queen Mary Universities lone working policy. Both are aware of Queen Mary Universities lone working policy which can be accessed here: http://hsd.gmul.ac.uk/A-Z/Lone%20Working/index.html. The PI will also keep a reflective diary throughout the research process to record her feelings throughout the process.

The Research team and the PI will meet monthly through out the duration of the research process. Within these meetings any issues that have arisen that have concerned the PI will be discussed and any action that is needed will be taken.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

The MS consultant and MS Nurse will identify potential patients of theirs who would be suitable to take part in the focus groups within their outpatient clinic over a duration of one month. If a patient meets the inclusion criteria and is happy to speak to the researcher, only then they will be approached. This will happen after their appointment while they are still in the outpatient department. The researcher will not approach patients without direction from the MS consultant or MS Nurse notifying them. This way we avoid approaching patients who would like to take part but are ineligible. The researcher will be aware of the vulnerability of patients when recruiting in the outpatient department. The researcher has received GCP training and will answer any immediate questions or queries individuals may have.

If patients would like to know more information about the study, they will be given verbal and written information in the form of patient information and consent form. The information will describe the purpose of the focus groups and describe that they will be asked to participate in tasks of discussion, analysis, idea generation and reviewing as well as contributing their experiences of living with MS. Informing the participants about the format of the research before they participate, will ensure they are willing to provide information in the focus groups. This information will also include information about details of how confidentiality will be maintained throughout the research process, how data will be recorded and their right to withdraw from the study or withdraw their consent at any point without having to supply a reason. Practical information such as details about building access, car parking and transport arrangements. Study participants will either have travel expenses reimbursed or will have travel arranged for them by the researcher.

The researcher will make a note of the patient's contact details (name, email, telephone number, address), the date the patient information is given to the patient and the researcher will confirm whether they are comfortable to be contacted in 24-48 hours by a preferred method of phone or email. The researcher will only obtain the patients contact details from the patient and will not share these.

Once each of the patient has read the patient information and has confirmed they would like to be involved (by either contacting the researcher, or at the follow up contact if they agreed to this), each participant will be telephoned or emailed as they prefer to arrange dates, times and potentially transport for the three focus group sessions.

Recruitment will approximately take 1 month.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

( ) Yes (•) No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

( ) Yes (•) No

A29. How and by whom will potential participants first be approached?

Patients will be first identified and approached by either the MS nurse or the MS consultant in charge of the patients care when visiting the outpatient department for their Neurology appointment. They will be then referred to the researcher and invited to participate in the research. Any immediate questions the participants may be answered by the researcher.

The MS Nurse or MS Consultant will not share any patient details with the researcher. It is up to the patient to share these with the researcher.

If participants would like to discuss the study with another member of staff then details of how to contact them via telephone or email are provided in the patient information.

A30-1. Will you obtain informed consent from or on behalf of research participants?

(•) Yes ( ) No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Informed consent will be obtained from each participant by the PI. Patient information and consent forms will be given to all participants. When participants confirm they would like to take part in the study, they will be telephoned to arrange dates and times for the three focus group sessions.

All participants will be asked to sign the consent form at the first focus group session in the presence of the PI, as each participant will have received information prior to the focus group. The PI will later scan and post a copy of this consent form to the participants and store the original

Recruitment will take approximately 1 month.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

(•) Yes ( ) No

A31. How long will you allow potential participants to decide whether or not to take part?

Once the PI has spoken to patients, provided them with the printed study patient information and confirmed they would like to be involved, she will make a note of the patient's contact details (name, email, telephone number, address), the date the patient information is given to the patient and a convenient time to contact them within 24-48 hours to enable them to remember the conversation, or at another convenient time agreed with them.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

Due to the nature of study we will be unable to recruit non English speakers and we do not have the resources to translate patient information or consents. Participants must be able to understand verbal and written English information.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- ○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ○ The participant would continue to be included in the study.
- ○ Not applicable – informed consent will not be sought from any participants in this research.
- ◉ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:
Participants may end their involvement at any time. We will advise them that we plan to keep all data collected from them before they end their involvement, unless they specify otherwise. However, if they require it, we will destroy all their data, which will be done securely. If data have been used in disseminations before withdrawal, we will advise participants that this information cannot be withdrawn.
Participants must tell us by the end of the study if they wish to avoid their data being included in reports, presentations and research materials. After this time, we can still remove data from our archives. If a participant withdraws from the study, they will not be replaced.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Access to social care records by those outside the direct social care team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☑ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals

- ☑ Use of audio/visual recording devices
- ☐ Storage of personal data on any of the following:
  - ☐ Manual files (includes paper or film)
  - ☐ NHS computers
  - ☐ Social Care Service computers
  - ☐ Home or other personal computers
  - ☑ University computers
  - ☐ Private company computers
  - ☑ Laptop computers

Further details:
Any data stored on a Queen Mary University computer of laptop will be anonymised. For monitoring and audit purposes, the Sponsor and individuals from regulatory authorities may need to view data generated by the study

A37. Please describe the physical security arrangements for storage of personal data during the study?

The original sound recordings will be stored by the PI on a Queen Mary University encrypted hard drive in password protected folders stored in a locked cabinet in the Blizard Institute building in Queen Mary University. Only the PI will listen to the sound recordings. All documents related to the study will be archived at the study site, including the listing of the identities of the participants involved in the study which will be kept separate from other documents.

Any data stored on a Queen Mary University computer of laptop will be anonymised.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

When patients sign the consent form they will be given a "Participant Identification Number" which will be a randomly generated number, generated from a simple Excel random function. This randomised number will ensure anonymity of the patients throughout the research and analysis process. Participants will remain anonymous with regards to any publications relating to the study unless they have requested to be named by either their name, pseudonym or initials in the publication.

The sound recorded data will remain on the recording device until back at the University building where it will be transferred to the storage device where it will be stored in a password protected folder on an encrypted hard drive. The sound recorders memory will be wiped.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The Professor of Neurology, Gavin Giovannoni, an authorized member of the research team, will access the Electronic Health Records system to save a scanned copy of the Patient consent form to patient medical notes. Patient notes will not be accessed again.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

Only the PI will listen to the sound recordings when transcribing the data in a private Queen Mary University office. All analysis activities within the research team will take place in this office.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title Forename/Initials Surname
	Miss Alison Thomson
Post	Lecturer in PPI and PES
Qualifications	University of Dundee, Dundee BSc Hons 2008 Interactive Media Design Royal College of Art, London MA RCA 2010 Design Interactions Goldsmiths, Uni. of London PhD Exp. 2018 Design Research
Work Address	64 Turner Street Blizard Institute, QMUL London
Post Code	E1 2AB
Work Email	a.thomson@qmul.ac.uk
Work Telephone	02078822367
Fax	

A43. How long will personal data be stored or accessed after the study has ended?

- ○ Less than 3 months
- ○ 3 – 6 months
- ◉ 6 – 12 months
- ○ 12 months – 3 years
- ○ Over 3 years

A44. For how long will you store research data generated by the study?

Years: 20
Months: 0

A45. Please give details of the long term arrangements for storage of research data after the study has ended. *Say where data will be stored, who will have access and the arrangements to ensure security.*

The original sound recordings will be stored by the PI on a Queen Mary University encrypted hard drive and stored in a locked cabinet in the Blizard Institute in Queen Mary University of London building. All documents related to the study will be archived at Queen Mary University of London, including the listing of the identities of the participants involved in the study which will be kept separate from other documents. All documents relating to the study will be retained for at least 20 years after the end of the study before being destroyed in line with the then existing secure Queen Mary University of London practice. Patient identifying data will be securely destroyed within 12 months of the study recruitment according to current Queen Mary University of London practice at the end of the study.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

◉ Yes ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Travel expenses will be reimbursed for patient travel to and from the focus group sessions. Refreshments will be provided for the participants in the break time in each focus group session. Participants will also be able to keep the cardboard 9 Hole Peg Test that they were posted at the start of the study if they wish.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes ◉ No

Please give details, or justify if not registering the research.
The research will not be registered on a public database, as there seems to be none for this specific study area. If the REC can recommend a relevant database, we have no objections to registering the research.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- ☑ Peer reviewed scientific journals
- ☑ Internal report
- ☑ Conference presentation
- ☑ Publication on website
- ☑ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

Identifiable personal data such as participants details (Names, addresses, email addresses and phone numbers) will be collected at recruitment from patients but will not be shared. When participants sign the consent form they will be given a "Participant Identification Number" which will be a randomly generated number, generated from a simple Excel random function. This randomised number will ensure anonymity of the participants throughout the research and analysis process.
When disseminating the results of the study, participants will have the option to have their names or a pseudonym included in the study publications, crediting their involvement.

A53. Will you inform participants of the results?

(•) Yes ( ) No

Please give details of how you will inform participants or justify if not doing so.
First and foremost, the researcher will return the key findings to the study participants along with a letter (sent via email or post) of thanks. This will also include a one page hand out summarizing the key findings from each focus group, and if they opted to be updated on the project development through the mailing list, they will also receive this.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- [ ] Independent external review
- [ ] Review within a company
- [ ] Review within a multi−centre research group
- [x] Review within the Chief Investigator's institution or host organisation
- [ ] Review within the research team
- [ ] Review by educational supervisor
- [ ] Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
The PI submitted the study protocol for peer review from two members of staff from Queen Mary University of London. Dr Klaus Schmierer is a consultant Neurologist who is a specialist in the area of MS research and leads on activities to improve the patient quality of life for people with upper limb issues. Dr Schmierer's comments regarded the scientific background of the study and clarified the inclusion and exclusion criteria. Following this comments, the PI included more relevant literature to this area.

Dr Karen Hoffman is an occupational Therapist based at Barts Health NHS Trust and has experience both treating people with MS but also developing PROMs. Dr Hoffman's comments regarded the methodology of the study and the qualitative analysis process. Following Dr Hoffman's comments, the PI re-arranged the layout of the protocol, clarified the primary and secondary objectives and re-wrote the data analysis section of the protocol.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:	10
Total international sample size (including UK):	10
Total in European Economic Area:	10

Further details:
Each focus group will comprise of, between eight and ten participants. Each participant will attend three focus group.

This sample will be purposively sampled to ensure that a range of experiences are captured and conveying in the group of participants that are involved in the study to ensure they are representative of the wider population of people living with MS. The MS Consultant and MS Nurse will be aware of this sampling method when they refer potential participants to speak to the research when recruiting in outpatients.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Each focus group will have between eight and ten participants. This number was decided upon based on previous research experience with focus groups involving ten participants, and the Barts MS Advisory Group, involving ten. As this is a qualitative study, the number of participants is small due to the role of their involvement in producing data.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Descriptive statistics will be used to analyse quantitative information to describe the sample explaining the range of EDSS and 9HPT scores of participants involved in both the focus groups and the online survey.

Qualitative data analysis will be used to determine how participants contributed to the PROM development and interacted as a group in this process. The process of Immersion/Crystallization will be used to analyse the data gathered from the focus group sessions. This method has been successfully used before by the researcher and in similar research around analysing experiential knowledge and will enable the researcher to consider the unique role that patients experiential knowledge plays in PROM development.

Data analysis will occur before (recording the initial engagement with the topic and any prior biases), during and after the data is collected to ensure it is high-quality. This will allow the researcher to consider the influence of their own background on the final results and interpretation.

The research team will then meet and establish key themes as a framework for initial analysis from the teams previous knowledge and experience of PROM development activities and professional experience. Involving the research team in the analysis process can ensure pitfalls such as drawing premature conclusions or inability to reach closure, are avoided.
Discussion of the three focus groups will be transcribed verbatim by the researcher and subsequently coded along with the researcher's handwritten field notes recording group interactions and taking into consideration any 'crystallizations', insights or reflections noted during data collection in the field notes. This is key as a secondary aim of the study, is to analyse the interactions amongst the participants within the focus group sessions.

The PI will immerse themselves in the data to create sub-themes can then be associated to key themes. The PI will then aim to validate the established sub-themes by rereading the text, searching for alternative hypothesis and interpretations. The analysis will be presented back to the research team.

After the three stages of focus groups have finished, the PI will feedback the conclusions reported to the participants. This will give the participants an opportunity to express any further reflections or points for discussion. After the researcher has completed the analysis, a final account of the data will be created for dissemination.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co−applicants, protocol co−authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Dr	Carol	Rivas
Post	Senior Lecturer (Associate Professor)		
Qualifications	PhD Medical Sociology, Queen Mary, London University (2012) MSc Cognitive Neuropsychology (Distinction) (evening course), Birkbeck, London University (1991-1993) BSc (Hons) Zoology (Upper Second), Queen Mary College, London University (1978-1981): specialised in physiology and behaviour		

	PGCAP (distinction) 2013
Employer	University College London
Work Address	SSRU, UCL 18 Woburn Square
Post Code	WC1H 0NR
Telephone	02076126923
Fax	
Mobile	
Work Email	c.rivas@ucl.ac.uk

	Title	Forename/Initials	Surname
	Professor	Gavin	Giovannoni
Post	Professor of Neurology		
Qualifications	MBBCh, FCP, CCST, PhD		
Employer	Queen Mary University of London		
Work Address	Blizard Institute, Centre for Neuroscience and Trauma 4 Newark Street		
Post Code	E1 2AT		
Telephone	02078828954		
Fax			
Mobile			
Work Email	g.giovannoni@qmul.ac.uk		

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: ( ) NHS or HSC care organisation
(•) Academic
( ) Pharmaceutical industry
( ) Medical device industry
( ) Local Authority
( ) Other social care provider (including voluntary sector or private organisation)
( ) Other

Commercial status: Non-Commercial

If Other, please specify:

Contact person

Name of organisation	Queen Mary, University of London
Given name	Sally
Family name	Burtles

Address	Joint Research Management Office (JRMO), Queen Mary Innovation Centre, Lower Ground Floor, 5 Walde
Town/city	London
Post code	E1 2EF
Country	UNITED KINGDOM
Telephone	02078827265
Fax	020 7882 7276
E-mail	s.burtles@qmul.ac.uk

Is the sponsor based outside the UK?
( ) Yes (•) No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- [x] Funding secured from one or more funders
- [ ] External funding application to one or more funders in progress
- [ ] No application for external funding will be made

What type of research project is this?
( ) Standalone project
( ) Project that is part of a programme grant
( ) Project that is part of a Centre grant
(•) Project that is part of a fellowship/ personal award/ research training award
( ) Other

Other – please state:

Please give details of funding applications.

Organisation	Horne Family Foundation
Address	1390 North McDowell Blvd., Suite G – #186, Petaluma
Post Code	CA 94954
Telephone	707-775-2466
Fax	
Mobile	
Email	info@hornefamilyfoundation.org

Funding Application Status: (•) Secured ( ) In progress

Amount: 60,000.00

Duration

Years:
Months:

If applicable, please specify the programme/ funding stream:

What is the funding stream/ programme for this research project?

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

◉ Yes ○ No

Name: Harriet Smith

Type of organisation:
○ NHS ○ Academic ○ Commercial ◉ Other

Please give further details of sub-contractor and main areas of delegated responsibility: Professional facilitator involved in leading the three focus groups

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
		Pushpen	Joshi
Organisation	Queen Mary, University of London		
Address	Joint Research Management Office (JRMO), Queen Mary Innovation Centre Lower Ground Floor, 5 Walden Street London		
Post Code	E1 2EF		
Work Email	sponsorsrep@bartshealth.nhs.uk		
Telephone	020 7882 6574		
Fax	020 7882 6574		
Mobile			

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/10/2017
Planned end date: 31/05/2018
Total duration:

Years: 0 Months: 8 Days: 0

A71-1. Is this study?

◉ Single centre
○ Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

☑ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?
○ Yes ○ No

A72. Which organisations in the UK will host the research?*Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

☑ NHS organisations in England	1
☐ NHS organisations in Wales	
☐ NHS organisations in Scotland	
☐ HSC organisations in Northern Ireland	
☐ GP practices in England	
☐ GP practices in Wales	
☐ GP practices in Scotland	
☐ GP practices in Northern Ireland	
☐ Joint health and social care agencies (eg community mental health teams)	
☐ Local authorities	
☐ Phase 1 trial units	
☐ Prison establishments	
☐ Probation areas	
☐ Independent (private or voluntary sector) organisations	
☑ Educational establishments	1
☐ Independent research units	
☑ Other (give details)	1
Unity Kitchen Cafe	
Total UK sites in study:	3

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

○ Yes ◉ No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The Principal Investigator will retain the right to audit any study, study site or central facility. In addition, any part of the study may be inspected by the regulatory bodies and funders where applicable. Quality control checks of procedures and documents will be undertaken should a need be identified. The sponsor delegates this responsibility to the Principal Investigator. An internal audit may be conducted by the sponsor representative.

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:* in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland**

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)
☑ Other insurance or indemnity arrangements will apply (give details below)

Queen Mary University of London is the sponsor and has arranged suitable indemnity concerning negligent harm to be in place for this study.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
☑ Other insurance or indemnity arrangements will apply (give details below)

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☐ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
☑ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

○ Yes ○ No ◉ Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For further information please refer to guidance.*

Investigator identifier	Research site		Investigator Name	
IN1	○ NHS site ◉ Non-NHS site		Forename Middle name Family name Email Qualification (MD...)	Alison Thomson a.thomson@qmul.ac.uk
	Institution name	Queen Mary, University of London	Country	UNITED KINGDOM
	Department name	Neuroscience and Trauma, Blizard Institute		
	Street address	4 Newark Street		
	Town/city	London		
	Post Code	E1 2AT		
	Country	UNITED KINGDOM		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

◉ Chief Investigator

○ Sponsor
○ Study co-ordinator
○ Student
○ Other – please give details
○ None

Access to application for training purposes *(Not applicable for R&D Forms)*
Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Alison Thomson on 13/09/2017 10:48.

Job Title/Post:	Lecturer in Public Engagement and Patient Public Involvement
Organisation:	Queen Mary University of London
Email:	a.thomson@qmul.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co−sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

   Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Dr Sally Burtles on 13/09/2017 16:00.

Job Title/Post:	Director of Research Services & Business Development
Organisation:	Queen Mary, University of London
Email:	sponsorsrep@bartshealth.nhs.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Professor William Gaver on 13/09/2017 11:58.

Job Title/Post:	Professor of Design
Organisation:	Goldsmiths, University of London
Email:	w.gaver@gold.ac.uk

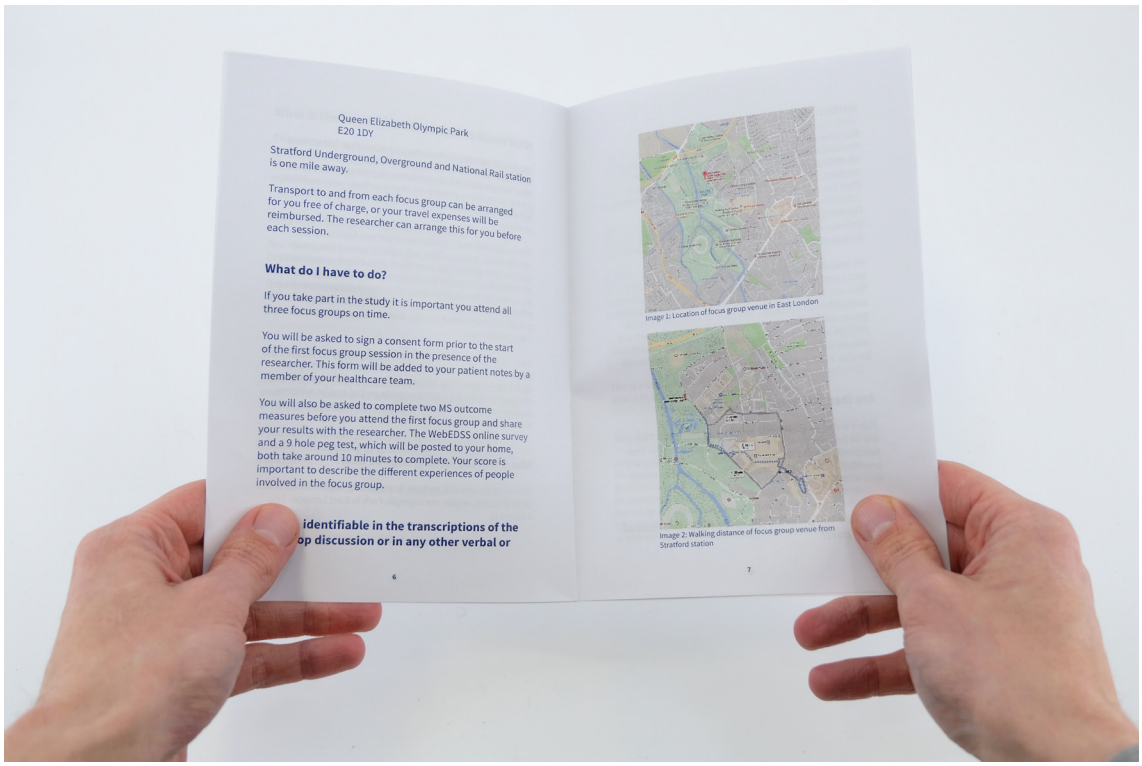
Academic supervisor 2

This section was signed electronically by Dr Alex Wilkie on 13/09/2017 11:46.

Job Title/Post:	Senior Lecturer
Organisation:	Goldsmiths, University of London
Email:	a.wilkie@gold.ac.uk

Appendix H: Participant information booklet


Measurement
on Our Terms
Patient study information
1


Queen Elizabeth Olympic Park
E20 1DY
Stratford Underground, Overground and National Rail station is one mile away.
Transport to and from each focus group can be arranged for you free of charge, or your travel expenses will be reimbursed. The researcher can arrange this for you before each session.
What do I have to do?
If you take part in the study it is important you attend all three focus groups on time.
You will be asked to sign a consent form prior to the start of the first focus group session in the presence of the researcher. This form will be added to your patient notes by a member of your healthcare team.
You will also be asked to complete two MS outcome measures before you attend the first focus group and share your results with the researcher. The WebEDSS online survey and a 9 hole peg test, which will be posted to your home, both take around 10 minutes to complete. Your score is important to describe the different experiences of people involved in the focus group.
identifiable in the transcriptions of the
op discussion or in any other verbal or
6
Image 1: Location of focus group venue in East London
Image 2: Walking distance of focus group venue from Stratford station
7

Measurement on Our Terms

Patient study information

Patient Information
Version 0.5
Date: 19th October 2017
Researcher: Alison Thomson
REC reference number: 17/LO/1684
IRAS project ID: 228062

Barts Health NHS
NHS Trust

Queen Mary
University of London

Hello,

We would like to invite you to take part in our research study, Measurement on Our Terms.

This research is being carried out by a researcher from the Barts Multiple Sclerosis (MS) Research Team at Queen Mary University of London (QMUL).

Before you decide whether to take part you need to understand why the research is being carried out and what it would involve for you.

Please take time to read this information about the study carefully. Ask us if there is anything that is not clear or if you would like more information; our contact details are at the end of this booklet.

Alison Thomson
Principal Investigator

What is the purpose of the study?

This study will explore how people with MS can contribute to the design of new ways to measure upper limb function. We plan to do this through three focus groups with people living with MS.

Why am I being invited to take part?

You have been invited to take part because you have been diagnosed with MS and you are a patient at The Royal London Hospital. We are very interested to hear the experiences of people whose upper limb function is affected by their MS. We would like to ask you to share your experiences with us.

Do I have to take part?

No, it is up to you to decide whether or not to take part in this study. A decision not to take part will not effect the standard of care or treatment you receive.

If you decide to take part you will be asked to sign a consent form allowing us to sound record the focus group discussions.

You are free to leave the study at any time.

What would be involved?

You would take part in three focus groups that will be held over a period of three months. The focus groups will involve other people with MS. If you decide you do not want to take part in every focus group then that is entirely your decision, but we hope to involve people who can commit to the three sessions.

The researcher and a professional patient facilitator will run the focus groups. They will start by asking the group questions to prompt them to think about their experiences of completing upper limb activities at home. The group will then create a survey that will gather these experiences from other patients online. At the next meeting, you will work as a group to discuss these results, then finally use them to create the new measure.

Each focus group will last about three hours and will be sound recorded, transcribed into print and then analysed by the researcher. You will receive a copy of the researchers' analysis and will be able to provide verbal and/or written comments on this. You will also be provided with a copy of the final research report, if you wish to receive it.

Where will the focus groups be held?

The focus groups will be held in a meeting room in the Unity Kitchen, within the Olympic Park in East London. The address is:

Timber Lodge Cafe

Queen Elizabeth Olympic Park
E20 1DY

Stratford Underground, Overground and National Rail station is one mile away.

Transport to and from each focus group can be arranged for you free of charge, or your travel expenses will be reimbursed. The researcher can arrange this for you before each session.

What do I have to do?

If you take part in the study it is important you attend all three focus groups on time.

You will be asked to sign a consent form prior to the start of the first focus group session in the presence of the researcher. This form will be added to your patient notes by a member of your healthcare team.

You will also be asked to complete two MS outcome measures before you attend the first focus group and share your results with the researcher. The WebEDSS online survey and a 9 hole peg test, which will be posted to your home, both take around 10 minutes to complete. Your score is important to describe the different experiences of people involved in the focus group.

Will I be identifiable in the transcriptions of the workshop discussion or in any other verbal or

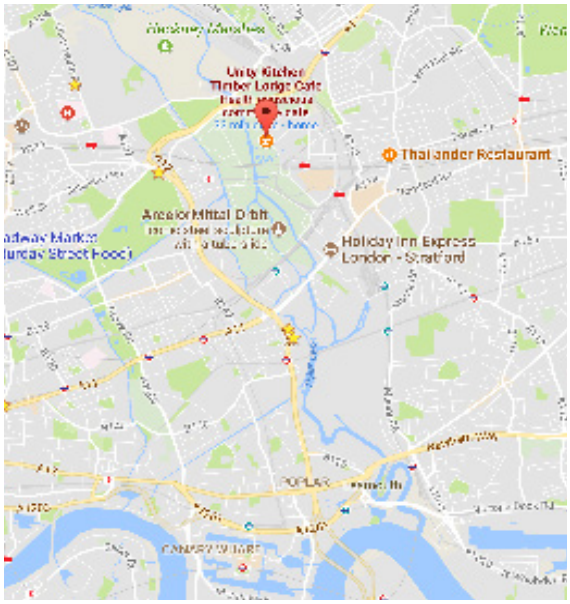


Image 1: Location of focus group venue in East London

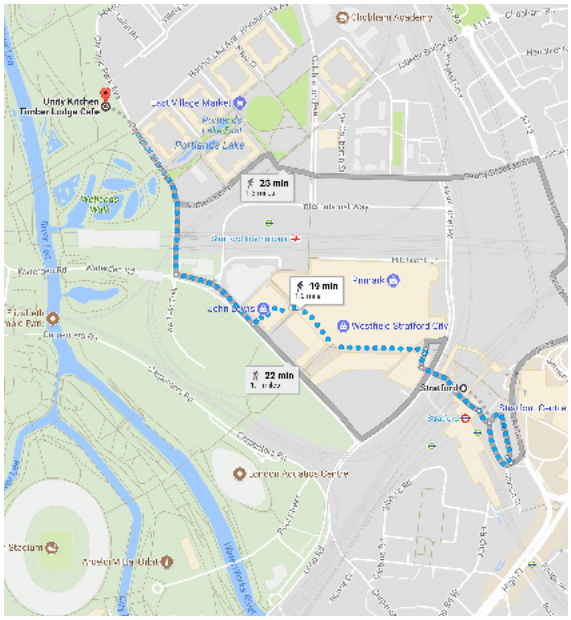


Image 2: Walking distance of focus group venue from Stratford station

written report?

No. You will not be personally identifiable in the typed transcriptions (you will be given a random participant identification number) or in any other verbal or written account. The sound files will not be heard by anyone other than the researcher.

For monitoring and audit purposes, the Sponsor and individuals from regulatory authorities may need to view data generated by the study.

All sound files will be stored securely in locked premises and electronic material will be password protected. Sound files will be destroyed confidentially twenty years following completion of the study. The draft analysis of each focus group will be given to everyone who takes part to read and provide written or verbal comments if they want to. Extracts may be published in articles and reports but no one would be able to identify you from these.

Are there any benefits to taking part?

There are no direct benefits to you as an individual. There will be benefits for other people with MS whose upper limb function is affected by their MS in the future. This study will provide insights to create information for people to record their activity.

What are the possible disadvantages and risks of taking part?

The study involves discussing your experiences of upper limb activities and how they are affected by MS. It is possible that, depending on the issues discussed, this could be difficult or concern you. Whilst other people in the discussion may provide you with support, you are free to leave if you want.

If taking part in the study causes you concern, please discuss this with one of the members of our research team after the focus group.

If you do not wish to discuss issues with the researcher, but wish to talk with someone who is independent of the research then the Patient Advice and Liaison service is available to you:

	Patient Advice and Liaison service
Tel:	020 3594 2040
Email:	pals@bartshealth.nhs.uk

This is a free, confidential service for patients which helps to deal with issues, and concerns you may have.

What happens at the end of the study?

After the third focus group you will be sent a draft of the researchers' final report. You will have the opportunity to provide comments verbally and/or in writing and may do so anonymously if you want. The final report will inform the design of future outcome measures. The report will be written up as a paper and submitted for publication in academic journals and presented at conferences.

At the end of the study, you have the option to join an email mailing list to receive updates about the results of the study.

Who is funding the study?

This is a non-commercial study which is being run by a researcher who will not receive any personal remuneration for taking part. The Horne Family Foundation are funding the research.

If I want to discuss the study further with a member of the research team who do I contact?

Please contact:	Alison Thomson Lecturer in Patient Public Engagement
Email:	a.thomson@qmul.ac.uk
Tel:	020 7882 2367

If I want to discuss the study with someone who knows about it, but is not involved in it then who can I contact?

Please contact:	Monica Marta Consultant Neurologist
Email:	m.marta@qmul.ac.uk
Tel:	020 7882 2677

Who has reviewed the research study?

The study has been reviewed and approved by the London-Stanmore Research Ethics Committee.

What if something goes wrong?

Queen Mary University of London has agreed that if you are harmed as a result of your participation in the study, you will be compensated, provided that, an injury was caused as a direct result of taking part in the study.

These special compensation arrangements apply where an injury is caused to you that would not have occurred if you were not in the study. These arrangements do not affect your right to pursue a claim through legal action.

What do I do now?

Please contact Alison Thomson by either email or telephone to confirm that you would like to take part in this study. You will then be contacted with the prospective dates and times of the focus group sessions. You will be asked to sign the consent form prior to the start of the first focus group session in the presence of the researcher.

Thank you for taking the time to read this information.

Appendix I: Participant consent form

Barts Health NHS Trust

Queen Mary University of London

PATIENT CONSENT FORM

Study Title: Measurement on Our Terms

Participant Identification Number:

Please **initial box** to indicate agreement:

1	I confirm that I have read and understood the patient information dated 19/10/2017 (Version 0.5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2	I understand that my participation in the three focus groups, each lasting three hours is voluntary. I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3	I understand that my participation will be sound recorded and I am aware of and consent to, use of these recordings for content analysis purposes.	
4	I understand that what I say in the focus groups will be transcribed, anonymised and used in publications (e.g. academic journals, conference presentations). I will be given a unique participant number. Confidentiality and anonymity will be maintained and it will not be possible to identify me from this quoted material.	
5	I understand that relevant sections of the data collected during the study, may be looked at by individuals from Queen Mary University of London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. For monitoring and audit purposes, the Sponsor and individuals from regulatory authorities may need to view data generated by the study	
6	I agree to take part in the above study.	

Name of Patient	Date	Signature
Name of Researcher	Date	Signature

One copy of this form will be for the patient and one copy will be added to the patients notes by a member of their healthcare team. The original will be kept by the Researcher.

Version: 0.4
Date: 19th October 2017
Researcher: Alison Thomson
REC reference number: 17/LO/1684
IRAS project ID: 228062

Appendix J: Questions for the Measurement on Our Terms meetings

Barts Health NHS
NHS Trust

Queen Mary
University of London

Focus Group 1

1. **Welcome and introduction**
   The facilitator will start by introducing themselves and the other researchers in the room. She will give a brief overview of the research study and check that all participants are happy to continue, and to be audio recorded. It will be made clear that if there are any questions, to either ask at any time, or mention to a researcher.

   Run through the timings of the focus group, mentioning breaks and refreshments.

   Safety information will be shared about the facilities and also ensuring confidentiality of any information that is shared within the focus group.

   As an ice-breaking activity, participants are to turn to person next to them and share an interesting fact. Then we share this with group.

2. **Background to the study**
   a. Introduction to the study topic area of PROMS and their role in upper limb function for people with MS.
   b. Introduce the aim of this research
      i. Run three focus groups to find out:
         1. What are the relevant UL activities for PwMS?
         2. How do you complete these at home?
         3. If we created a PPROM, what would this be?
   c. Process for developing PROM (FDA)
      i. Focus group 1 – Design online survey
      ii. Run survey
      iii. Focus group 2 – Discuss survey results
      iv. Focus group 3 – Develop format for new PROM

3. **Group Discussion**
   The facilitator will hold an open discussion with the participants around how their upper limb function, and the ability to complete everyday tasks has been affected by their MS.

   This will then lead onto a discussion about their experience of completing PROMS and the role and meaning of measurement in their lives. Is this something that they find important or useful?

4. **Break**

5. **Design an online survey to collect a range of UL activities:**
   This section will
   a. Design survey questions
   b. How should we collect the survey responses? E.g. text, written, video, image (non-identifiable)
   c. How will we discuss this information?
   d. Appropriate information for survey respondents - within the survey: consent, results.

Barts Health NHS
NHS Trust

Queen Mary
University of London

6. **Close and next steps**
   Thank them for taking part in the focus group and describe what the next steps are.

Focus group 2

1. **Welcome:**
   Outline session timing reiterating important information about logistics and confidentiality.

2. **Discuss survey results**
   Discuss the general response from survey including numbers of responses and any comments left relating to format of survey

   All of the participants will be given printed copies of the survey results and be asked to read through them all.
   - What are the common themes or categories of activities that come up?
   - Are there similar locations, formats or purpose of activities?

3. **Break**

4. **Create terms of measurement**
   What is a meaningful way to measure these activities? Is it success if completing it or doing it quickly? Are headings “impossible, difficult, easy” meaningful or useful?

5. **Close and next steps**

Focus Group 3:

1. **Welcome:**
   Outline session timing reiterating important information about logistics and confidentiality.

   a. Re-write new instruction
   b. How and where does this PROM exist
   c. What does it do, and enable people to do

2. **Designing the PROM:**
   a. Decide method of administration: self-administration, interview, group activity
   b. Format of administration: paper based/ digital
   c. Group to decide naming of the tool
   d. Develop instructions of use.
   e. What to do with results

3. **Break**

Barts Health NHS Trust

Queen Mary University of London

4. Close and next steps for dissemination

Thank them for taking part in the study and describe what the next steps are. Discuss logistics of compensation for travel expenses.

Appendix K: Responses from MOT online survey to Question 1.

Respondent number	What hand and arm (upper limb) activities do you find difficult, due to your MS?	Are there any tips, hacks, devices or tools you use to help you complete any of these activities?	Are there any upper limb activities that you avoid doing?
	Activity 1: Opening crisps		
3	Crisp packets or anything that requires the double grip and pull apart motion		
9	Opening crisps		
38	Opening packages eg. Crisps		
	Activity 2: Knife and fork		
2	I can't hold cutlery		
9	Using a knife to cut		
17	Cutlery use		
19	Eating with cutlery		
24	I can just about hold a knife, but can't apply enough pressure to be of any use		
29	If I concentrate on picking up something I can often do it, but for everyday things like picking up cutlery these usually end up flying across the room		
38	Using a knife and fork		
45	I eat with a small dessert fork - heavy weighted cutlery impossible as hand is also weak		
48	Using a fork to stab food on my plate (weakness)		
62	Using a fork	Use scissors a lot invaluable to open packets, cut up food, chop onions etc so I can eat using a fork in my right hand	
64	Some of my fingers do not do what I want them to when holding cutlery		
65	Gripping cutlery is more and more difficult, sometimes I cannot cut up my food by myself and things fall off my fork/spoon before they get to my mouth	Rubber band wrapped around cutlery handles is a great help	
66	Cutting food and eating it as hands to weak		
72	Using cutlery		
74	Using a knife and fork		
84	Using cutlery	I eat mainly with just a fork	
88	Use knife for difficult to cut food		
	Activity 3: Carrying liquids		
3	I also have intention tremor so carrying liquids like drinks or food is quite unpredictable and often messy. I occasionally just drop things for no apparent reason which I assume is muscle spasm in my hands		

20	Holding open containers of liquids	I ask people in cafes to carry coffee to my table for me. I take a mug with a sealing lid so I can carry a coffee at work	
30	Carrying a mug of hot coffee - particularly difficult as i use a crutch in my good hand	Making a flask of coffee	
34	Carrying hot drinks		
37	Holding things such as glasses regardless full or empty		
62		Use a tea trolley to get plates/ glasses from worksurface to table and to move things around the house	
	Activity 4: Dealing with coins		
4	Picking up coins/small objects	Slide coins, small items to edge of table. Never use change from purse when paying	
28	I started separating my coppers out of my purse prior to 2008 when I was diagnosed as I was finding them too fiddly		
35	Pick up small objects (coins etc.)		
48	Picking the correct coin from my purse (fine motor skills)		
69	Getting money out of purse		
	Activity 5: Pills out a blister pack		
20	Handling tiny tablets	.	
38		Pill Cutter to help with medication as i cant snap medical pills in half	
48	Picking up my daily tablet from the work surface (dexterity)		
65	Have difficulty opening tablets and pills; not enough strength to open bottles especially child proof tops, awkward to push pills out of foil sheets and dropping them while putting them in my mouth		
69	Sorting tablets into medidose container		
77	Getting pills out of blister packs and not dropping them		
82	Picking up pills out of pill container		
	Activity 6: Changing sheets		
24			Changing bedclothes is pretty impossible and need help, but most other tasks are possible single handed
51	Changing beds		
	Activity 7: Tying shoe laces		
9	Tying shoe laces		Laces
11	Shoe Laces		
24	Tasks I find difficult are dressing, including pulling up trousers and tying shoe laces		
27	Shoe laces		Tying shoe laces
29	Clothes with buttons or zips can be challenging so to are laces		

30	Fastening shoe laces		
34	Tying shoes		
54	Doing up shoe laces		
60	Shoes (laces)		
62	Tying shoe laces		
65	My husband ties my shoelaces		
69		Slip on, velcro or zip shoes. Luckily I can wear children's sizes	Shoe laces
71	Tying shoelaces		
	Activity 8: Sewing		
4	Sewing		Sewing
8	Sewing		
11	Using a needle and thread		
13	Threading a needle		
21	Threading a needle		
22	While I can type and knit I cannot do it for any length of time		I no longer sew and embroidery was one of my hobbies
33	Gripping knitting needle		
34	Threading a needle		Sewing
42			Fine motor activities, like sewing
48	Threading a needle, controlling fabric through a sewing machine, cutting accurately		Sewing
51	Sewing		
52	When fatigued my fingers lose strength, ability to grip and do not react quickly - moving them becomes more concious I struggle to grip small things - keys, zip pulls, sewing needles etc and when I am fatigued my reynaud's is often also worse so my fingers are more numb and have less sensation so I can't feel very well		I can't sew if I am tired becuase my fingers won't grip the needle
65			Can no longer sew or mend clothes
69	Sewing		
83			I try to avoid really fiddly jobs like sewing buttons
	Activity 9: Using keys		
7	Putting key in lock with left hand		
29	I used drop my key when opening the door and then overbalance when picking it up. I now have my keys attached to my hand bag with a extendable ski pass holder		
30	Turning the ignition key		
42	Using a key in darkness		

46	Finding keys etc in bag/pocket without looking		
52	When fatigued my fingers lose strength, ability to grip and do not react quickly - moving them becomes more concious I struggle to grip small things - keys		
	Activity 10: Playing piano / guitar / instrument		
3	I can no longer play the violin or piano		
8	Playing the recorder		
11	Too much piano playing worsens the numb feeling in my fingertips and can become painful at times	Take breaks if playing the piano	
21	Playing piano - the runs not the chords		I rarely play the piano these days
50		Changed from an acoustic 6 string guitar to a Bass (4 strings) guitar	
83	My arms tend to feel weak after playing the piano and the slight numbness in my fingertips makes prolonged playing sometimes uncomfortable, almost painful		
	Activity 11: Lifting heavy pots while cooking		
33	Lifting and tipping saucepans to get out contents		Serving from full saucepans
34	Lifting pots while cooking		Anything need to hold especially hot pans
41			Heavy cooking pans
46	Lifting a pan of pasta/potatoes for a family of 4	.	Lifting anything heavy
48	Draining water from a pan of cooked vegetables, tipping cooked food from a pan (eg beans)		
49	Carrying pots		
51	Lifting saucepans		
54			Anything that needs lifted with 2 hands is avoided such as pots, casserole dishes
60	Transferring food from saucepan		
84	Lifting heavy pans		Lifting pans
	Activity 12: Hair; washing, drying, brushing, straightning		
4	Doing hair (arm tires easily)		
9	Washing hair		
18	Doing my hair - tricky to keep my hands/arms above shoulder height		
19	Unable wash back legs hair		
25	Washing my hair		I haven't found another way of washing my hair other than someone else doing it for me

29	If I concentrate on picking up something I can often do it, but for everyday things like picking up hairbrush		Sometimes I'm not able to dry my hair with dryer due to tremors and wealness
30	Fasten my hair back		
37	Washing my hair		
45	Tremor in right arm means it is impossible to blow-dry hair		
48	Washing my hair		
54			Straightening hair is impossible with just one arm/hand so I've gone curly
60	Washing Hair		
65	Difficulty using hair dryer and brushing/combing hair, some days I cannot lift my arms high enough and find the hair dryer to heavy to hold steady		
72	Washing hair in shower		
76	Have noticed that my hair, partner's hair and the dog's coat feel much coarser now so I think i have lost some fine touch but it does not affect day to day tasks		
82	Holding blow dryer above my head to dry hair		
84	Brushing hair		
	Activity 13: Typing		
1	Typing on computer	1-, 2-finger typing	
3	All keyboard activities and touchscreen to a lesser extent		
14	Typing on a Computer		
18	Typing after a while		
19			Typing ipad or computer
21	I type slower with more mistakes		
22	While I can type and knit I cannot do it for any length of time		
27	Typing on a computer		
30	I now only use my left hand for typing and operating the mouse		
36	Typing after a long period of time		
39	Typing on a keyboard		
40	Typing is usually ok but have slowed mouse cursor down so it's less sensitive		
43	Typing, especially on a smart phone		
51	Typing on computer		
54	Typing		
58	Typing to fill this in is making my right hand burn		

62	Typing		
67	With prolonged typing		
72	Typing		
74	Typing		
76	Typing can be difficult at times, especially if the keys are quite raised (like the ones at work)		
	Activity 14: Touchscreen tech.		
2	Using touchscreen tech - texting		
3	All keyboard activities and touchscreen to a lesser extent		
19	ipad		Typing ipad or computer
20	Problems with tremor, pins and needles in fingertips, security of grip, judgement of grip, strength and repeated actions; eg writing, using touchscreens		
29	Tremor in arms and hand cause me to double click when using keyboard on laptop/phone/tablet		
34	Touch screens (correct pressure)		
43	Typing, especially on a smart phone		
82	Any repetitive activities, holding cell phone in one hand, texting, using my finger to delete e- mails, pressing iPad control buttons, when scrolling with finger down iPad accidentally activate other sights due to finger jumping		
	Activity 15: Handwritting		
3	Handwriting longer than a sentence or two becomes both illegible and painful		
4	Writing		Writing unless I really have too
8	Handwriting	Cursive handwriting	
9	Writing		Writing
11	Lots of writing	Not really at the moment though I don't spend too long writing in one go	
14	Writing		
16	Writing by hand		
17	Writing		
18	Handwriting		
20	Writing		Writing more than a line
22	Writing is difficult as I cannot feel properly or control my fingers to hold a pen		
23	Writing		
26			Writing

30	Sometimes I'm unable to write		
34			Handwritten forms on bad day
35	The left hand has become dominant, but not able to handwrite		
36	Writing with a pen		
39	Holding a pen and controlling it to write		
40	Only thing I can't do with left hand is write & writings v difficult for me now & sometimes impossible. So I often avoid writing or ask others to do. This has all happened in the past year. I work full time in an office job	Weighted fat pen. Helps a bit	Writing
42	Hand writing up to a certain extent		
45	Tremor in r hand/fingers makes it impossible handwrite		Hand-writing
46	Writing legibly is tricky unless i concentrate		
65	My handwriting is unrecognisable and my signature could be anyone! due to not being able to grip the pen firmly and my hand not moving smoothly across the page		
66	Writing		
68		I steady my hand with my other hand, and use my left arm for a lot of tasks (except for writing.)	
71	Writing is becoming more difficult	Have to write more slowly	
72	Writing with affected dominant hand	I use a very fat pen for writing which makes the task easier and my penmanship more legible	Writing
73	Writing		I try to avoid writing
74	Writing		
79	Writing for any length of time	With writing I generally hope for the best	
82	Handwriting gets worse as my hand tries holding pen		
83	Finding handwriting more difficult these days - seem a little shaky		
84	Writing-gripping the pen properly		
89	Sometimes if i am doing extensive writing my letters start to smush together		
	Activity 16: Putting on Jewellery		
4	Putting on earrings and necklace		
9	Jewelry necklace		
29	I can no longer put on jewellery on my own like bracelets and necklaces		
30	Fastening a necklace	Wearing necklaces which go over my head	

37	Putting on earings		
39	Jewellery fastenings eg necklaces, earrings		
46	Can't do up necklaces		Rarely wear jewellery
51	Fastening jewellery		
54	Putting on jewellery		
61	Difficulty with putting earring in right ear		
65	Can push earrings through my pierced ears but cannot do up the back		
81	Eg putting jewellery on		
88	Cannot put on earrings or necklaces that need to open and close		
	Activity 17: Make up		
4	Putting on makeup		
48	Applying makeup (weakness to keep my hand up at face height, fine motor movement to apply eyeliner/ mascara/lipstick)		
58	Lifting right arm e.G. Putting on mascara causes a burning sensation all along		
73	Putting on make-up		
84	Putting on makeup		
	Activity 18: Putting on a bra		
9		Bra on	
20	Doing up a bra	My husband helps me do my bra	
45	Cannot wear a bra so use a light sports bra with no hooks	Cannot wear a bra so use a light-weight sports bra with no hooks	
48	Fastening / unfastening my bra		
63	Bra the hardest thing		
65	My husband ties my shoelaces and does up my bra for me		
79	Doing up the back of my bra	I put my bra on with the clips on the front, do them up, twist it to the back and slip the arm straps up. Almost anyone who wears a bra can show what I'm talking about. I usually buy sports bras now	
	Activity 19: Opening a jar		
2	Opening jars		
13		Jar openers	
29	Weakness in hands means I'm unable to undo jar lids		
33	Opening jars		
43		Grippers for jars	
51		Gadget to open jars	

53	Opening jars		
67	Opening jars		
78	Opening jars		
79	Opening tight jar lids or small bottles		
84	Opening jars		
	Activity 20: Chopping vegetables		
21	Chopping vegetables or fruit with a knife quickly		
23	Chopping food		
46	Chopping tricky veg eg butternut squash, sweet potatoes, celeriac		
48	Chopping vegetables, peeling vegetables		
52			I don't use sharp knives eg chop vegetables etc if I am fatigued because of the risk of cutting myself
60	Cutting food	Chopping board with spikes to hold food	
62		Chop onions etc	
67	I also have difficulty chopping vegetables		
72	Chopping vegetables		
81	I am not as fast at preparing food (cutting/cooking) and have to look at what I am doing all the time		
84	Chopping vegetables		
	Activity 21: Getting dressed		
9	Putting on socks, putting on knickers and trousers		
24	Tasks I find difficult are dressing, including pulling up trousers and tying shoe laces	Most activities can be achieved one handed and selecting easier to wear clothing is essential. Elastic waist track bottoms and avoiding buttons are a couple of examples	
32	Putting on socks		
34	Dressing		
36	Putting on socks on myself or on my 7 year old son		
44	Tucking tops into trousers		
48	Putting my arm into a shirt, gripping clothing to be able to pull it on (pants, socks, trousers etc), fastening buttons, pitting the zipper in the zip, gripping the zip on jeans to pull the zip up		
50	Putting socks on		
51	Getting dressed		
60	Dressing: buttons, zips, pulling up trousers, putting on / off tight fitting tops, socks		

62	Left arm/hand weakness. So difficult activities are getting dressed/undressed, doing buttons or zips	Wear trousers that when done up go over my hips, use a belt to keep up.	
	Activity 23: Buttons		
2	Sometimes buttoning shirts & blouses		
3	As all small buttons		Buttons
4	Small buttons		
9	Doing up buttons.		Buttons
11	Doing up buttons		
13	Intricate things like fastening buttons		
14	Closing buttons		
16	Buttoning shirts	Don't buy clothes with buttons	Buttoning shirts
17	Buttons		
21	Using buttons on clothing, especially small ones		
26			I find doing up buttons of a shirt difficult
29	Clothes with buttons		
35	Or open the buttons		
42	Buttoning my shirts		
45	Difficult to do up buttons		
46	Fastening a button		
48	Fastening buttons		
50			Avoid wearing buttoned shirts
53	Doing up shirt buttons sometimes		
54	Buttons		
56	Doing up buttons		
60	Buttons		
62	Doing buttons		
63	Buttons	Keeping buttons on blouses done up all the time	
65	I can no longer do up buttons and zips are becoming more difficult		
66	Buttons		
71	Doing up buttons		
72	Buttons		
73	Doing up small buttons		
74	Buttons		Buttons
77	Doing up cuff buttons		
78	Doing buttons up behind my back as numb fingers seem to need sight		

Appendix L: Responses from MOT online survey to Question 2.

Respondent number	What external factors affect how you complete upper limb activities?
External Factor 1: Time of day	
3	If I am exhausted from doing too much physically generally hand function also declines. I am better doing anything physical in the morning, late afternoon my nadir and evening I am improved again like the morning
4	Amount of time spent, as day goes on gets harder
13	Time of day (it's worse in the evenings) and after activity (if I am tired or have done a lot that day it is worse)
18	Time of day
20	Everything is worse in late evening
22	My hand gets worse throughout the day. It is best early morning
24	I manage better in the morning before fatigue sets in and makes things much harder
29	My legs and arms tend to kick out more in the evening or at night in bed. But sometimes if i have overdone it the day before i can get it earlier in the day
32	Morning - 10:30
33	Evenings, after a couple of hours of knitting
36	First thing in the morning or anytime if feeling especially fatigued
37	Easier for me in the morning
41	The evening is worse, when I'm tied
43	Worse as day goes on. Much better first thing in the am
49	Any time of day on my own
50	Symptoms deteriorate as the day progresses and with fatigue
51	Time of day, how tired I am, whether I have exercised at all that day
53	Time of day (much more capable in the mornings)
54	Left side does not function when tired so need help afternoons and evenings
55	I get more fatigued as the day goes on so I try to do any jobs I need to do in the morning
60	Time of day
62	What time of day it is and wnen I've taken my muscle relaxant tablets that maybe allows me to do a few activities
63	Time of day
66	Afternoons and evenings are worst
67	Worse later in the day
68	Seems to be more of a problem in the afternoon
71	In morning dressing is very slow, particularly buttons. In evening wrists are weaker and manual dexterity fades
72	Time of day
77	I'm better in the morning, before fatigue sets in, unless I've had a shower in which case i need time to recover before doing anything
79	I generally function better in the morning
80	Time od the day-night
82	Later in the day more fatigued
84	If i get out of bed late, eg. An hour later than normal at weekend, i feel much weaker doing tasks than on weekdays. If the day before has been busy, again, i am weaker the day after

86	Late in evening
External Factor 2: Duration of activity	
2	Overuse affect spasticity / spasm
3	As with all activities i am much better at doing anything for the first couple of minutes muscle fatigue in fingers hands wrists arms shoulders kicks in very quickly.
4	Amount of time spent, as day goes on gets harder
18	length of the activity
30	How long I've been doing the activity for, i.e. I can write for a short while.
34	repetition &/or prolonged lift of heavy pots
67	Worse with repetition
76	Obviously worse when I am tired and if I get stressed at work about how long it is taking me to type
83	Playing the piano can be exhausting, especially at the end of a long day or if I have to play for a long time such as during a church service
External Factor 3: Temperature	
2	Cold temperatures
3	I am very sensitive to cold and become quite rigid and tremor ridden when cold, hot weather improves my function. As above i need to use a walking stick, so in very cold weather when my hands get cold it's greatly limits my ability to use the stick and so to walk
4	If too warm or too cold I am either wobbly or stiff
7	Cold weather
14	Also when it is warm
16	Heat
29	Temperature
34	Needle threading length worse when tired or hot
55	If it is hot weather I feel very fatigued
58	Worse if cold. If my hands get cold they feel numb and get cold burn
65	If I am hot I find it more difficult to do anything as my arms/hands just stop working
66	Heat makes them worse
69	I suppose a bit worse when tired or too hot or hands cold
70	I think my hands are worse if they are cold
73	Gripping is difficult in cold weather.
74	Body temperature (weather or fever)
77	When it's very hot I find everything more difficult
79	I generally function better if it is cooler
81	Being tired and heat very much affects me. I work inside so that usually helps, but being in australia if it is summer and hot out then when i first start sometimes it takes a while to cool off and then I can be extra clumsy when I start
82	Heat
86	Weather; too hot and too cold
External Factor 4: Visibility	
42	If I cannot see what I'm doing, darkness
63	They work better when I can see what I am doing with them. Doing up my bra is sometimes impossible.
External Factor 5: Emotion	
2	High emotion
28	Nothing particular maybe feeling flustered

29	Stress (particularly when I was at work as I was not supported at all and so fatigue set in and I was unable to move my upper body, I would also shake a bit like the nodding dog!!
37	Other people yelling, unexpected activity, emotional situation
39	How I'm feeling, whether I'm feeling rushed
40	Generally unaffected by external factors. But stress does make tremor worse
53	How confident I feel because of fatigue and how well my balance is at the time
76	Obviously worse when I am tired and if I get stressed at work about how long it is taking me to type
79	I generally function better if I'm feeling cheerful
External Factor 6: Being watched	
11	Probably fumble a bit more if other people are around waiting for me/ watching
20	Also if I'm in unfamiliar surroundings, situation or with unfamiliar people, everything is harder and worse
39	How I'm feeling, whether I'm feeling rushed
53	I do not attempt the activities unless a family member is present
60	Being watched
65	I find that I become more clumsy if someone is watching me
76	Others waiting for me etc. (Shared hospital ward computers)
83	If I am surrounded by people and they're watching me then my handwriting tends to be worse and i'm more shaky. I do struggle with my nerves playing in front of other people
External Factor 7: The activity before	
5	After exercising, or after work (I do eight hour shifts at a care home)
9	If I am tired, rushing, in a different environment
11	Writing is harder if hand has been used previously on other tasks
13	After activity (if I am tired or have done a lot that day it is worse)
18	What I did before
20	What I've been doing before
63	What I have been doing before
68	Also relates to how hard I've been working
72	How well I slept, how exerted I am
77	If I've had a shower in which case I need time to recover before doing anything
89	Fatigue is always worse at the end of a workday and the end of a workweek. These make my grip strength and weakness worse
External Factor 8: Other	
15	Ongoing infection worsens it
17	Only really can dress myself in my ofwn home where everything is the exact height, in the correct place etc
21	Level of fatigue, how I am feeling (weak or not)
23	At home mum and partner prepare food & make & carry drinks
73	Worse in the few days before my tysabri infusion, gripping is difficult in cold weather
78	The higher the fatigue the more difficult, tending to drop things more if am talking or multitasking
81	Being tired and heat very much affects me. I work inside so that usually helps, but being in australia if it is summer and hot out then when i first start sometimes it takes a while to cool off and then i can be extra clumsy when I start. The level of neuropathic pain I get in my arms/ hands is also a factor
88	Husband helps with earrings and jewellery , do not wear clothes with buttons, cooking virtually impossible at any time of day. I hate not being able to function independently

Appendix M: Responses from MOT online survey to Question 3.

Participant number	Are there any tips, hacks, devices or tools you use to help you complete activities?
Tech. solution	
2	I have haptic feedback on my mobile phone and can unlock the phone with a fingerprint sensor
3	Voice input for anything electronic, I recommend Dragon nuance version 10 and above for serious paperwork on both PC and Mac
26	I use Dragon dictation software because of difficulty writing or using a computer key board
27	Voice operation facilities some help
62	Use voice to dictate texts
67	I use audio recording for some computer work
74	Voice to speech
Change type of object	
4	Wear dangly earrings with hook rather than butterfly, wear other jewellery with magnetic clasps
8	Using a large threaded needle
15	Tried weighted silverware and push buttons. Can be hard to push
18	thin narrow keyboard
19	Light weight cutlery
21	Use a pen with a rubber gripper
27	Elastic shoe laces, dish washer, slicing tools, electric nail cutter/filer
30	Wearing necklaces which go over my head; use an electric tin opener; make more use of the dish washer
34	Use scissors instead of knives to cut herbs, fish etc.
41	I use the smallest and lightest weight kettle for the kitchen, made out of plastic
43	Use scissors to open bags
45	Cannot wear a bra so use a light-weight sports bra with no hooks, get my eyelashes and eyebrows tinted at beauticians, similarly nails manicured. Vanity, I know!
46	Magnetic fastenings for necklaces. I'm thoughtful about what pans I buy
49	A bottle opener some times work or ask neighbor
54	Electric tin opener is great, use dyson stick vacuum as cannot pull plugs out of sockets anymore, sketchers with no laces are amazing. Bought an automatic car as moving gears stick was impossible
56	Food processor would help probably
62	Wear trousers that when done up go over my hips, use a belt to keep up. Use stylfile clippers with rubber band, for grip, on to cut finger nails -clippers with scissor action so easier to use. Use scissors a lot invaluable to open packets, cut up food, chop onions etc so I can eat using a fork in my right hand. Use clothes pegs to close packets instead of fiddly metal ties. Magnetic necklace clasps
65	Rubber band wrapped around cutlery handles is a great help, velcro fastenings are good for shoes, using cups and mugs with big handles, wearing clothes that slip on with no buttons or fiddly fastenings
69	Slip on, velcro or zip shoes. Luckily I can wear children's sizes
72	I use a very fat pen for writing which makes the task easier and my penmanship more legible
79	I usually buy sports bras now
85	Holding things: opt for plastic instead of glass/ceramic, try to pay close attention to my "gripping"
Introduction of a secialist device / tool	
3	I have perch stools and grab rails everywhere at home

13	I use kitchen devices such as jar openers and grips
18	Special mouse
20	Using a stylus for my mobile. I use a mouse with the laptop
20	I take a mug with a sealing lid so I can carry a coffee at work
23	Weighted wrist bands but they make my arms tired
29	Ski pass holder. I use a hot water machine at home where I place my cup under the nozzle and push a button which dispenses the correct amount of water for my whatever size cup I am using. I use a walker whichapart from helping me balance also holds myhandbag do that I do not having to carry it
30	Have a steering knob fitted on my car
38	Pill Cutter to help with medication as i cant snap medical pills in half
40	Weighted fat pen. Helps a bit
43	Needle threaders, grippers for jars, proper pen
51	Electric can opener, gadget to open jars,not storing foodstuffs in high or very low shelves, unless I can pick them up with a grabber. A low trolley so that things can be dragged or pushed rather than lifted
53	Aid to open jars; use of a perching stool; rail to help me pull myself out of bed
55	I use a grab stick to help me pick up things
58	Have a vertical mouse at work. A ambidextrous, cordless vertical mouse has been ordered for work and will hopefully help
60	Sharp knives with special handles. Fat handled peelers (oxo). helping hand grabbers, chopping board with spikes to hold food
76	Have taken far too much work home because of the typing issue but also use a dictaphone a lot more than others (have secretarial support thankfully)
79	I have some plastic grippy material and a battery operated jar opener. I also have an aid to help open ring pull cans
84	Wrist weight helps with writing
	Change in technique
7	Use right hand
9	Bra on. Back to front. Use teeth and hand to open packets
20	My husband helps me do my bra and does all cooking and refills the kettle with only a small amount of water. I ask people in cafes to carry coffee to my table for me
24	Most activities can be achieved one handed and selecting easier to wear clothing is essential. Elastic waist track bottoms and avoiding buttons are a couple of examples. I believe targeted exercise helps maintain some strength and sure that using a seated row machine at the gym has improved my ability to pull up trousers. A stress ball has helped keep a small amount of grip strength
28	Licking fingers
30	Using the handle of a wooden spoon to open ring pulls on tins; I've learnt to do many things with my non dominant hand as that is not affected; put some items on to a lower shelf so I can reach them; making a flask of coffee
32	Kneel on floor next to bed or similar support
34	Sit while cooking so balance isn't an issue, use a dryer indoors for washing (both hanging rack and tumble drier), batch prepare meals so can just microwave when ready, sit to dress and especially socks/shoes
41	I fill the water to the minimal level for boiling. I use plastic plates for camping and outdoor eating as they are light weight to carry
46	My non-dominant hand is getting better at doing buttons etc as that side is less damaged by the MS
53	Make sure I am sitting down to complete the activities
59	Some aspects of driving are easier when I am wearing gloves
61	I use my left hand more. I am left handed but over time used my right more and more but have now returned to being more of a lefty
62	Use a tea trolley to get plates/glasses from worksurface to table and to move things around the house. Use a wheely bag to transport shopping from shop to car then car to house.

63	Keeping buttons on blouses done up all the time
64	My husband
68	I steady my hand with my other hand, and use my left arm for a lot of tasks (except for writing.)
71	Have to write more slowly
77	My family :-)
78	Stabbing the milk top!
79	I put my bra on with the clips on the front, do them up, twist it to the back and slip the arm straps up. Almost anyone who wears a bra can show what I'm talking about. I usually buy sports bras now
81	Using air con to maximum (esspecially in car, when I am en route somewhere). Buying food that is prepared as much as possible (stuff that is already cut up). I live alone, and with fatigue and food prep being a problem if it is not easy it will not happen (and I refuse to live off microwave meals). Managing fatigue is important for me (it increases neuropathic pain, decreases ability to use hands, and I keep the meds to a minimum as the effect my cognition and increase fatigue and ability to work)
84	I eat mainly with just a fork, use thumb to press aerosols, use teeth to open tight tubes and lids (I know! idiot!) microwave veg instead of heavy pans of water
85	Opening containers: rubber gaskets/hot water/wet cloth/husband. Boots: dont' wear them
Rest / take breaks	
11	Take breaks if playing the piano
14	Resting, asking my Family for help, eating ice-cream
18	Breaks
52	Rest until possible even if that means just going to bed and trying again tomorrow
83	Not at the moment but I try not to write or play the piano too much in one go
86	Try to relax, if evening put things away and usually go to bed